LEARNING LOCAL CARE:
AN ETHNOGRAPHY OF CAREGIVING IN HAWAIʻI

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ABSTRACT

This thesis is an ethnographic account of caregiving and end-of-life decision-making in Hawai‘i. By participating in family caregiver classes provided by a local hospital, I detail how the socioeconomic realities of living in Hawai‘i and the biomedical authority of medical professionals actively work against the interests of caregivers who make health decisions based on both cultural values and economic limitations. Through the embodied experience of practicing care in the home, caregivers selectively reject the biomedicalization of care and organize their actions around the institution of family. As evidenced through examples from two key informants the circumstances of family caregivers are varied and complex, leading to a variety of experiences and creative solutions. Though the embodied experiences of family caregivers disillusions them to the examples provided through the family caregiver classes, the classes succeed in providing a platform for family caregivers and professionals to hold meaningful discussions.

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CHAPTER ONE
INTRODUCTION: LEARNING HOW TO CARE

Introduction

I met Patty for our interview at a local shopping center—neutral ground. The idea of conducting an interview at the hospital or university made both of us uncomfortable for reasons we could not quite explain. To discuss the struggles of our dying family members in a sterile, professional environment gave the impression of exposing personal information regardless of the fact we were about to have an recorded interview. A small pastry shop helped to calm our mutual nervousness and the bustle of a small coffee shop provided the backdrop to which we began to discuss the harsh reality of family caregiving in Hawai‘i, one of the most difficult states in which to navigate end-of-life care (American Association of Retired Persons 2011). As our conversation settled into a comfortable rhythm, I finally posed the question, “Have you talked with you parents about [what kind of care they want to receive] at all?” After a brief pause, Patty replied:

> They want to stay at their home…but to be honest we haven’t really gone that far because it’s so overwhelming day to day that I haven’t go that far yet…this is part of my research too, I’m trying to decide what’s best or how to look at things…am I able to take care of them depending on what’s going to happen? Obviously if it’s more of a really heavy into the medical side of it…I do the basic stuff now but with working more than full time and trying to survive here in Hawai‘i…

After a brief pause to consider the heaviness of her statement, I quietly voiced my affirmation, “yeah, it’s hard.” Family caregivers in Hawai‘i face a daily struggle against the mainstream practice of medicine and economic pressure to gain power over both the practice of end-of-life care in the home and the bodies of the family members they made a commitment to aid. We sipped at our drinks, and with a focused yet thoughtful face she said “yeah and so…right now it’s not a question that’s been answered or addressed yet.” Though our conversation continued on for

more than an hour, I remained struck by the sense of indeterminacy that comes with planning for the slow decline of a family member's health.

There is no one way to practice end-of-life care. While the biomedical focus on extending lifespans has transformed "once fatal conditions into chronic illnesses such that people require ongoing and often intensive assistance for years or even decades," many communities are unable to afford forms of institutionalized care such as hospice or nursing homes (Buch 2015:278; Field 1996). Still other communities continue to rely on younger family members in multigenerational households to provide care for the elderly, including communities in urban Hawai'i (American Association of Retired Persons 2011, 2015; Buch 2015). In Hawai'i, families are frequently unable and unwilling to place their loved ones in institutionalized care for a variety of socio-economic reasons (American Association of Retired Persons 2011). What happens when you cannot afford the steep cost of institutionalized care? How do socioeconomic disparities manifest in Hawai'i, and how do they affect end-of-life caregiving? What happens to the socioeconomic livelihoods individuals who assume the role of caregiver? How does this engage with larger theoretical questions of how nation-states conceive of and provide care for the bodies of their citizens? As my conversation with Patty exemplified, the realities of caregiving in Hawai'i are complicated and multi-faceted.

This thesis explores end-of-life care in Hawai'i through the lens of family caregiver classes offered by a local hospital. My experiences—both in my personal life and in my fieldwork—inform my perception of the events and shape my understanding of caregiving. Throughout this thesis I return to the themes of biomedicine as social control, bodily autonomy, and the body as the locus of meaning and agency. Biomedicine as social control invokes Foucauldian notions of biopower, or the "numerous and diverse techniques for achieving the

subjugations of bodies and the control of populations," and ethnographic examinations of biomedicalization (Foucault 1976:140). I argue that biomedical power and authority are destabilized by the embodied practice of care in the home. While medical professionals continue to uphold biomedical power in their daily practice, family caregivers disrupt this system through alternative caregiving strategies and a rejection of professional knowledge. Caregivers ignore biomedical authority in favor of strategies which achieve the best result in line with economic limitations, but I posit that family caregivers remain accountable to the family as an institution which governs bodies. By framing both medical professionals and caregivers as accountable to institutions of power, I am able to explore how language acts as a proxy for experience as these groups communicate within the context of the family caregiver classes while upholding their differences and bureaucratic categories.

Next, I demonstrate how anthropological discourses of citizenship and autonomy are applicable to future directions for end-of-life care in Hawai‘i. I include this discussion because it calls into question assumptions of biomedicine, such as biological citizenship and to what extent end-of-life care should be supported by the state (Petryna 2013). Through the search for autonomy over end-of-life care family caregivers come into conflict with biomedicine, resulting in the subversive practice of care in the home which works to reinforce the family power structure and care as a social obligation. The struggle of care as a subversive practice allows caregivers to invent a biomedical nostalgia for a time when family caregiving was common practice—this nostalgia then serves as a mechanism to contest the locus of power over care.

Finally, I call into question the body as the battleground in which conflicting beliefs and interests play out. Here, I would like to note that the purpose of this thesis is not to judge who is a good caregiver or who is a bad medical professional; instead, I hope to shed light on the

inequalities and gaps in the end-of-life care system of Hawai‘i and provide the selfless individuals who have dedicated their lives to this issue with information to move forwards. I begin this chapter by developing biomedicine as a method of social control, particularly in relation to end-of-life care. I then describe anthropological theory regarding citizenship and autonomy, a particularly pertinent discussion given the history of Hawai‘i as colony of the United States of America. Finally, I explore the body as a locus of meaning, agency, and docility and describe my methodology for this thesis.

Biomedicine as Social Control

Michel Foucault changed the way generations of scholars conceptualize power and the body through his writing (1975, 1978, 1980, 1988, 1991). According to Foucault, "the control of society over individuals is not conducted only through consciousness or ideology, but also in the body and with the body" (1978:27). He explored the ways in which this societal control manifests most notably in prisons and the clinic. *Discipline and Punish: The Birth of the Prison* (1975) demonstrates effective control over bodies through the example of Jeremy Bentham's Panopticon, a building which governs prisoners through visibility and the constant fear of surveillance. Through this concept of panopticism, bodies are rendered self-governing and docile.

Birth of the Clinic: An Archaeology of Medical Perception (1975) introduced the notion that medical professionals have control over specialized language which bestows them with the unique ability to see into the bodies of patients. Through language and semiotics, medicine and health transcend technical knowledge which is both arbitrary and conventional, and become a system deeply connected to and influenced by culture (Foucault 1975; Good 1994; Martin 1987). Medical professionals are socialized into this particular way of thinking about the human body,

and in turn medical professionals attempt to socialize caregivers into this way of thinking through the family caregiver classes (Good 1994; Martin 1987). By utilizing specialized language and technology, doctors and other medical professionals bestow upon themselves the unique ability to "gaze" into the human body. In *Birth of the Clinic: An Archaeology of Medical Perception*, he wrote that "it was no longer the gaze of any observer but that of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention" (1975:89). Through the institution of biomedicine and the inaccessibility of biomedical knowledge to the public at large medical doctors are able to exert a particular type of control, or biopower, over the human body. The combination of biopower and surveillance results in Foucault's concept of governmentality, or a kind of power which "seeks to monitor, observe, measure, and normalize individuals and populations" (Clarke et. al. 2003:165). Through governmentality, the individual not only accepts biopower over their bodies, but enforces it upon themselves.

Biomedicalization is a political economically-fueled process through which both the practice of medicine and the production of medical knowledge are "extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine" (Clarke et. al. 2003:162). Biomedicalization necessarily includes "the commodification of health, the elaboration of risk and surveillance, and innovative clinical applications of drugs, diagnostic tests, and treatment procedures" (Clarke et. al. 2003:165). Moreover, "the biomedicalization healthscape boldly and predictably features technoscience, its interventions, and its promises for the future" (Clarke 2010:131). The earlier process of medicalization took place in the late nineteenth and twentieth centuries, and introduced "the professionalization and specialization of medicine" as a unique realm of knowledge production

into which only those individuals with proper training could gain insight (Clarke et. al. 2003:163). With the rise of the clinic and hospital-based research, doctors specialized into experts on various organ systems and disease and developed a special language through which to convey ideas about these new paradigms of the body. Donna Haraway notes that "the power of biomedical language—with its stunning artifacts, images, architectures, social forms, and technologies—for shaping the unequal experience of sickness and death for millions is a social fact deriving from ongoing heterogeneous social processes" (1991:365). These processes always refer to this style of Western (allopathic) medicine, in contrast to homeopathic medicine, because of a long imperialistic tradition of Eurocentric thought. For Europeans and Euro-Americans this does not represent a problem, but in places with a pre-existing or diverse traditions of health-related knowledge, like Hawai'i, the medicalized emphasis on Western medicine represents an epistemological dilemma.

A crucial component of the biomedicalization process is the introduction and normalization of medical technologies. These technologies—both external from and within the body—expand upon the power of medical professionals to see into and control knowledge about the inner-workings of bodies. According to Haraway (1991), biomedicalization has resulted in a transformation of human bodies. "Bodies have become cyborgs—cybernetic organisms—compounds of hybrid techno-organic embodiment and textuality" (1991:379). Kelly A. Joyce builds upon this argument to illustrate "how MRI exams produce a 'located, embodied, and contingent' truth that merges bodies, machines, and work practices to constitute a particular body in medical practice and social life (Haraway 1997:230)" (2008:61). Through the use of technologies, such as MRI, doctors and other medical professionals further biomedicalize the body, and further sequester the ability to understand the ways in which medicine acts upon the

body into the realm of the professional. Such medical technologies are "transformed into a technology of truth that not only [symbolize] quality of health care but also [have] the power to reveal facts about one's medical condition" (Joyce 2008:2). In order for medical care to be deemed sufficient it often requires the application of a medical technology, marking the inextricable connection between technology and biomedicine (van der Geest et. al. 1996).

The individual receiving treatment, however, is generally unaware of the assumptions biomedicine creates and enforces regarding the body. Emily Martin, in writing about the ways in which biomedicine has shaped women's perceptions of the female body and its processes, wrote that cultural assumptions about events which we "conceive of as biological, and often medical" are actually a complex integration of the two (1987:12). While certain biological conditions must come together to create a body capable of the processes of menstruation and childbirth, the culture of biomedicine influences how individuals perceive the cause and effect of these events. Martin states that "medical culture has a powerful system of socialization which exacts conformity as the price of participation" (1987:13). This system encourages individuals in biomedicalized societies to engage with the body in particular, medicalized ways. Other medical anthropologists, including Kelly Joyce, demonstrate other ways in which biomedicine socializes individuals to understand the body in different ways. Through her ethnography *Magnetic Appeal: MRI and the Myth of Transparency*, Joyce establishes the MRI as a powerful tool through which the body is reimagined and recreated through the power of technological sight, rendering the previously unseen as potentially dangerous and medicalized (2008).

Charles Briggs presents one of the most compelling examples of how biomedicine can be used as a mechanism of social control in *Stories in the Time of Cholera: Racial Profiling During a Medical Nightmare* (2004). Briggs demonstrates how "ideologies and practices of social

inequality—particularly ways of perceiving and relating to persons in terms of their ability to internalize modern hygiene and bio-medical conceptions of health and disease" contributed to the death of hundreds of Venezuelan citizens during a cholera outbreak in Venezuela (2004:21). Biomedicine, more specifically an adherence to the principles of biomedicine, was used to inform government officials, public health specialists, and medical professionals who was deserving of biomedical treatment. Therefore, when an individual or group exists outside of or in opposition to the dominant biomedical ideologies they run the risk of losing their access to biomedical technologies and treatments.

The study of caregiving in Hawai‘i contained within this thesis provides further insight into how biomedicine works as a mechanism of social control with the potential to disenfranchise individuals and groups already subject to socioeconomic inequality and racial discrimination. Hawai‘i is "one of the most expensive states in the country for nursing home care" and many families living in the state cannot afford the cost of professional help in the home (American Association of Retired Persons 2011:4). As a result, family members are often find themselves in the role of 'caregiver.' Before continuing, it is necessary to clarify the role of 'caregiver' and define the collection of activities encompassed by the term 'care.' The desire or necessity of remaining in the home creates a reliance on a family member or close friend to provide daily care—a role defined as 'family caregiver' to distinguish this unpaid position from paid 'professional caregivers' who receive formal medical training. The type of care provided by family caregivers is circumstantial, and directly dependent upon the needs of the person they are caring for. Care can include—but is not limited to—managing prescription medications, administering medication, completing documents (including taxes and bills), creating diet plans, tube-feeding, assisting with hygiene, and providing transportation.

This style of caregiving is time-consuming, with the average family caregiver providing 24.4 hours of care per week (American Association of Retired Persons 2015). More intensive care requires the caregiver to be within the immediate proximity of the care recipient for the majority of the day, which connects care to the historic role of women within the home (Buch 2015). Recent studies confirm the persistence of this trend, and one report found that as many as "six in ten caregivers are female" (American Association of Retired Persons 2015:14). Oftentimes these predominantly female caregivers are unable to maintain employment due to the demands of providing care, further compromising their economic security within an already expensive end-of-life care landscape (American Association of Retired Persons 2011, 2015; Towey 2017). Therefore, how individuals uphold (or do not uphold) the expectation of performing a particular role within the biomedicalized end-of-life care system has the potential to provide valuable theoretical insight into the anthropological study of biomedicine as social control.

Citizenship and Bodily Autonomy

Each day, various forms of invisible violence go unaided by humanitarian efforts, development organizations, and both federal and state governments. Georgio Agamben (1998, 2005), drawing upon the Greek words *zoe* versus *bios*, noted a difference between the manner in which an individual lives and the biological condition of life. From this difference he derived a theory of 'bare life,' denoting a life which has been stripped of rights and reduced to only biological life or death. 'Bare life' intersects with politics through 'states of exception,' theorized as a space outside of law or government in which individuals are reduced to only biological lives and the government increases its power over bodies. Building on these theories, Akhil Gupta

theorized that poverty should be seen as an "a direct and culpable form of killing made possible by state policies and practices rather than as an inevitable situation in which the poor are merely 'allowed to die' or 'exposed to death'" (2012:5). Gupta argues that while the poor are frequently seen to be "excluded from national projects of development, democratic politics, and cultural citizenship," included peoples can also be killed as the result of seemingly arbitrary decisions made by those in power (2012:6). Therefore, it becomes important to explore the ways in which states selectively bestow the benefits of citizenship and ignore the suffering of others.

The question of citizenship as it relates to access to the benefits of development, democracy, and aid is frequently debated by anthropologists. In her study of Chernobyl, Adriana Petryna explored the concept of 'biological citizenship,' which she describes as "a massive demand for but selective access to a form of social welfare based on medical, scientific, and legal criteria that both acknowledge biological injury and compensate for it" (2013:36). More people will always require services and benefits from the state than can be provided, resulting in suffering and violence. Charles L. Briggs similarly writes about citizenship during the cholera outbreak in Venezuela. He writes that "these people died, by and large, because racism affected the distribution of vital government services such as health care and water and waste treatment facilities, as well as economic and other resources, and affected how individuals who received them were treated" (2004:20). He partially accounts these unequal distribution patterns to his notion of 'sanitary citizenship,' a mechanism which allows the state to decide who is deserving of access to resources. The counter to the 'sanitary citizen' is the 'unsanitary subject,' a person who is "judged to be incapable of adopting this modern medical relationship to the body, hygiene, illness, and healing" and therefore is undeserving of medical resources during a time of illness

(2004:24). In both 'biological citizenship' and 'sanitary citizenship,' the state uses certain criteria to decide who receives limited resources and differential treatment.

Sovereignty can be defined as "the ability to control, and have autonomy over, one's life in whatever manifestation the society of which a person is part articulates what the fundamental parts of 'life' are" in relation to indigenous peoples (West 2016:6). One of the many reasons a group might seek to regain sovereignty is control over the decision-making process which determines 'citizenship' and access to rights and resources. A key component of disenfranchisement and dispossession is ideology which "blurs and makes invisible both the violence and the structural conditions that keep some people in power and others disempowered (Marx and Engels 2001:64)" (West 2016:5). Indigenous scholar and anthropologist Audra Simpson, however, pushes contemporary understandings of sovereignty in her examination of Kahnawà:ke Mohawks who have been displaced and dispossessed by settler colonialism in North America. She notes that "sovereignty and nationhood are expressed differently from these essentialized modes of expectation by the settler state and its law, and how this difference pushes up against these other extremely narrow forms of judicial interpretation" (2014:20). The disconnect between the settler state and the dispossessed society creates a tension. Simpson suggests that the refusal of United States or Canadian citizenship acts as a sovereignty claim for Kahnawà:ke people, and that a Kahnawà:ke "sovereignty may exist within sovereignty" of the settler state (2014:8).

In Hawai'i, tension is derived from a disconnection between the way biomedicine creates end-of-life care and the way society at large practices care in the home. What is conceived of as fundamental to biomedicine differs from how individuals in the home are both able to practice care based on socio-economic limitations and how they conceptualize the practice of care in the

home. Sovereignty in the way which Paige West (2016) and other authors write refers specifically to the experiences of indigenous peoples. Therefore, the tension experienced by non-native people living in Hawai‘i must be understood through the lens of a struggle for autonomy over end-of-life care and as an aspect of settler colonialism which seeks to erase the Native.

Excluding the native Hawaiian people whose ancestors arrived from the South Pacific thousands of years ago, the ancestors of everyone who currently resides on the Hawaiian archipelago arrived on the islands in the recent past from elsewhere through settler colonial processes. Following in line with the work of Jonathan Y. Okamura, I distinguish the different groups of people in Hawai‘i by ethnicity rather than race, because “people in Hawai‘i attribute greater social significance to the presumed cultural differences that distinguish groups from one another than to their phenotypic differences” (2008:6). More specifically, each of these groups has a unique historical trajectory which led them to settle in Hawai‘i under very different socioeconomic circumstances.

European Americans make up the majority of the population in Hawai‘i, though there are significant differences between those families who arrived at different points in history. For example, Portuguese Americans who arrived in Hawai‘i as early as 1870 to work in the booming plantation industry consider themselves a separate group from the European Americans who arrived later. Many Portuguese Americans in Hawai‘i continue to occupy the working class, while more recent European American arrivals possess the finances necessary to find housing in a cut-throat economy where the price of living continues to skyrocket. Altogether European Americans continue to benefit from a higher socioeconomic status in Hawai‘i and are not only more accepting of biomedical practices, but more aptly situated to take advantage of such services. Other large ethnic groups in Hawai‘i include Japanese Americans, Filipino Americans,

and Chinese Americans. In particular, Filipino Americans came to Hawai‘i to work as plantation laborers during the height of the plantation culture from 1906-1946 (Okamura 2008). It is important to note that all of these groups, though often disenfranchised and marginalized themselves, are participating in settler colonial processes. Therefore, they benefit from colonial systems in ways Native Hawaiians do not. Furthermore, while many of these groups embody and refer to themselves as ‘locals,’ it is important to note that the term ‘local’ comes to displace and erase Native Hawaiian claiming of place as a mechanism of settler colonialism (Okumura 2008). Though the term ‘local’ is utilized throughout this thesis to refer to the embodied identity of ‘localness,’ in no way does it seek to dispossess Native Hawaiian people. As predominantly working class families, these groups have suffered from lower socioeconomic status and unequal access to education and other services. When considering end-of-life decision-making and the economic realities which influence this process, it is necessary to remember that significant socioeconomic inequalities persist between the different ethnic groups living in Hawai‘i, influencing the ability to pursue certain pathways within end-of-life care.

Through colonial processes, Hawai‘i was subjected to “the effects of Christianization and the introduction of the Anglo-American legal system” which have resulted in violence and called into question the ‘biological’ or ‘sanitary’ citizenship of native Hawaiians throughout the archipelagos’ settler colonial history (Kauanui 2018:2). I feel at this stage it becomes necessary to clarify the boundaries of what this thesis *does* and *does not* set out to do in regards to these topics. I employ the aforementioned contrast between sovereignty and autonomy in order to distinguish the settler colonial struggle with autonomy over end-of-life care from the health-related aspects of the Hawaiian sovereignty movement. Native Hawaiians are largely absent from this thesis, in part because the processes of settler colonialism actively seek to erase these

narratives. The Hawaiian sovereignty movement is inextricably connected to these issues in ways which are much more complex than can be addressed in this medical anthropologically-focused thesis on family caregivers who are geographically located in Hawai‘i. Though the Hawaiian sovereignty movement is also concerned with issues of health, medicine, and bodily autonomy, in this thesis I discuss autonomy over end-of-life care only as it pertains to non-Hawaiian residents of Hawai‘i in a way which runs the risk of but intends not to further erase the Native Hawaiian narrative.

Today, O‘ahu is home to roughly one million permanent residents, and hospitals have branches all over the island to serve those residents who do not live in the capitol city of Honolulu. Major public hospital networks include The Queen’s Health Systems, Hawai‘i Pacific Health, St. Francis Healthcare System of Hawai‘i, and Kuakini Health System. Due to the remoteness of the Hawaiian archipelago, residents of the state are entirely dependent on the services offered by these hospitals unless they are willing to pay upwards of one thousand dollars to visit the mainland’s western coast to seek medical care. Several non-profit organizations have been created out of a need for improved communication among different stakeholders in the end-of-life care network, such as the Hawai‘i Family Caregiver Coalition and Kōkua Mau. While Kōkua Mau is a network of organizations which seek to improve access to information on end-of-life care and resources, the Hawai‘i Family Caregiver Coalition is more focused on social and political activism. Most recently, the Hawai‘i Family Caregiver Coalition helped to pass the Kūpuna Caregiver Act 102. This legislation, the first of its kind in the United States, provides family caregivers who are employed full-time with monetary compensation to be used for care-related expenses, such as transportation or food-delivery services. Furthermore, several hospitals

and care-related facilities have developed caregiver support groups or classes to satisfy an unmet need for family caregiver resources and end-of-life care decision-making.

The Body as the Locus of Meaning

The body as a specific object to be theorized by medical anthropology was pioneered by Nancy Scheper-Hughes and Margaret Lock (1987). In "The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology," Scheper-Hughes and Lock posit "three perspectives from which the body may be viewed" (1987:6). The first of these "three bodies" is the individual body which can be understood through phenomenology and lived experience. The second is that of the social body, which refers to "the representational uses of the body as a natural symbol with which to think about nature, society, and culture" (Scheper-Hughes and Lock 1987:7). The third body is that of the body politic, through which the body is understood as an object of social and political control. Each of the 'three bodies' is a distinct way of theorizing the body in medical anthropological research, though oftentimes these bodies are overlapping and existing at once.

Pierre Bourdieu (1992) expands upon this understanding of the body with his theories of *habitus*, described as ingrained and inherent ways of knowing the world which are at least in part shaped through social interactions. His writings were heavily influenced by the work of Marcel Mauss (1968) and Maurice Merleau-Ponty (1964; 1973; 2012). Mauss theorized *habitus* as the elements of culture which are connected to either the body or daily practices, and was particularly interested in movements. Though not the first scholar to write about the notion of *habitus*, one of Bourdieu's key contributions was the concept that *habitus* is shapes the human body. In other words, Bourdieu theorized that *habitus* is embodied experience. Theories attempting to link decision making and interaction to socialization processes were written as

early as the 1960s with Thomas C. Schelling's tacit coordination (Collins 1994) and Erving Goffman's *Interaction Ritual: Essays on Face-to-Face behavior* (1967). An explicit turn to recognizing the body as the site of culture—including embodiment theory and phenomenology—did not arise the early 1990s.

More contemporary anthropological scholarship has explored phenomenology as a useful framework for understanding embodiment and how knowledge is gained through embodied experience. Phenomenology can be defined as the study of meanings and subjective experience (Becker 2002; Csordas 1990; Desjarlais and Throop 2011). While culture shapes larger worldviews and values, individual embodied experience has the power to shape perspectives and more personal understandings of the world (Desjarlais and Throop 2011). Scheper-Hughes and Lock's (1987) individual body can be understood as existing within an intersubjective lifeworld, drawing upon the phenomenological theories of Edmund Husserl (1970), Martin Heidegger (2010), and Maurice Merleau-Ponty (1964; 1973; 2012). Everything that exists within an individual's lifeworld is part of their lived experience, and these experiences can be shared amongst individuals resulting in intersubjective—or shared—experiences.

In regards to this thesis research, through the embodied practice of care within the home, family caregivers transform their bodies into "the subject of culture" rather than "an object to be studied in relation to culture," and reaffirm their identity and individual agency by performing care in creative ways (Csordas 1990:5). From the research perspective of a medical anthropologist, the bodies of caregivers can be theorized through each of the 'three bodies' developed by Scheper-Hughes and Lock (1987). The practice of end-of-life care in the home is part of the family caregivers' embodied experience, while their understanding of how to practice

care is informed by and reinforced through social relationships. Furthermore, caregivers are subjected to sociopolitical control and surveillance through the institution of biomedicine.

Methodology

The focus of this thesis is end-of-life decision-making and lived experiences of family caregivers in Hawai‘i; therefore, I decided against the use of quantitative methods so as to preserve the individualistic and diverse nature of these circumstances. The thematic focus on the embodied experience of caregiving would be difficult to capture without calling upon my own experiences as a family caregiver to inform the decision I made while conducting fieldwork. Feminist anthropologist Lila Abu-Lughod highlights that "all knowledge is partial and from an embodied perspective;" therefore, to not bring my own experience would be a failure to properly engage with my research informants and create the most complete picture of end-of-life care in Honolulu possible (1990:15). Similarly, I kept my interview questions open-ended and unstructured to encourage natural conversation with the similar goal of preserving each individual's story and allowing myself to adjust questions as necessary.

I feel that it is important to address the emotional subject matter contained within this ethnographic work. Over the course of my fieldwork, several of my informants lost family members or occasionally even the informants themselves to old age. Though the research contained within this thesis is directly concerned with end-of-life caregiving, I believe that by conducting participant observation through the family caregiver classes I mitigated emotional duress to my informants. Each informant had control over their participation in the family caregiver classes, and even further in their participation in my project. Furthermore, rather than directly requesting to interview specific participants, I provided the entire class with my contact

information and encouraged them to reach out to me on their own if they were interested in talking about their experiences as a caregiver.

This thesis is the result of approximately one month of participant observation research in family caregiver classes, many informal conversations, several interviews with key informants, and attendance at various events in the end-of-life community of Honolulu, Hawai‘i. I formally observed six caregiver classes on both week nights and weekends. Outside of formal participant observation I attended several additional class sessions as part of my preliminary fieldwork. Each class session lasted two hours; therefore, I completed approximately twelve hours of in-class participant observation. The classes are most frequently hosted on Monday and Wednesday evenings and Saturday mornings, and the timing for each session is decided based on the schedule of the instructor, as well as the schedules of the participants. Since many of the participants work full-time, in addition to providing care in the home, the most convenient times for the family caregiver classes are weeknights and weekends. The classes are widely advertised throughout the hospital on bulletin boards, and a full-page ad is run in the free local newspaper each week.

The family caregiver classes were created through a collaborative effort between a hospital administrator and CEO who recognized a need for information regarding end-of-life care in the community. Through the creation of these classes, they hoped to pioneer a trend which would eventually spread throughout the various hospital networks and combat generational gaps. Participants would be actively encouraged to share information about the classes with friends and family to allow for the organic growth of the program. The classes successfully began in June of 2016, and have since expanded to include multiple offerings each week. The caregiver class instructors came from a wide-range of professional backgrounds,

including: nurses, government officials, physical therapists, dieticians, and non-profit organization employees. They are often recruited through personal connections, and prepare their own lectures and activities. Caregiver class participants are also diverse, ranging from current family caregivers to hospice nurses or other medical professionals who want a refresher course in a particular topic. During my fieldwork, the majority of participants were women slightly over middle age. Excluding myself, only one participant was under thirty years old, though several participants were well over sixty years of age.

The caregiver classes were located on the second floor of an administrative building on a hospital campus in a residential Honolulu neighborhood. Signs clearly marked the path through the quiet administrative hallways to a sign-in desk placed outside of the room, where participants were required to check-in and verify payment. The classroom itself was a large, well-lit meeting room with several rows of thin lecture tables. The organization of the room changed significantly depending on the particular class session and the teacher's activity plans. Some class sessions favored a lecture-style arrangement, in which tables were organized into rows facing the front of the room. The front of the room was marked by the presence of a table, functioning as an informal lectern, and a projector for presentation slides. Each seat at the tables was equipped with handouts of the presentation slides, and these handouts were strategically placed only at tables in the front of the room to encourage participants to sit as close to the speaker as possible. The rows of tables were closely spaced, and did not allow for a wide-range of movement. Other times, the tables were shifted towards the outside edges of the classroom to create room for activities in the open space created in the center of the classroom. Regardless of the classroom organization, I sat in the right-hand side of the front of the classroom.

My role as a researcher was made transparent to the participants by both the caregiver class staff and myself. At the beginning of each class session, I was introduced as a graduate student researcher from the University of Hawai‘i at Mānoa who was conducting research with the permission of the hospital administration. Over the course of my fieldwork, I received informed consent from forty-six individuals. I conducted interviews with six individuals, of which two became my key informants with which I conducted several interviews over approximately three months. During the collection of informed consent, I personally answered additional questions regarding my role and intentions. Though I sat among the caregiver class participants during each class session, I was perceived by the participants to be an authority figure on par with the hospital administrators and instructors. I was frequently asked questions regarding the class topic or end-of-life care more broadly. On occasion, I was also invited by the staff to help set-up for the caregiver classes. This involved preparing activities or assisting with technology.

Outline of the Thesis

The body of the thesis will consist of three chapters which build upon my field notes, interviews, and informal conversations. I organized the chapters to flow from more traditional anthropological critiques of power to envisioning a community-centered approach to care in Hawai‘i in an attempt to mirror my understandings of end-of-life care throughout my fieldwork experience. As I began my fieldwork, I brought with me the literature I had prepared in the process of defending my research proposal; therefore, my first argument relates directly to Foucauldian notions of power. My next point of focus was the social interactions captured in the family caregiver classroom, which related most closely to the process of knowledge transfer and

how individuals learn to be biomedical caregivers from medical professionals. Moving from the caregiver classroom to one-on-one interviews with caregivers, I attempt to capture the daily realities of family caregivers in Honolulu, Hawai‘i and explore the means through which caregivers can find agency and meaning. Ultimately, I offer an anthropological analysis of the biomedicalization of care as contextualized through the caregiver classes and life histories of individual caregivers.

Chapter Two introduces the reader to the family caregiver classroom and provides a critique of Foucauldian notions of power in relation to both caregiver class professionals and participants. First, I utilize ethnographic vignettes to accustom the reader to the realities of end-of-life care and decision-making in Hawai‘i. I introduce the theoretical and practical concept of biomedicalization as a tool for examining and understanding the caregiver classes, and use this concept to demonstrate how medical professionals uphold Foucauldian power structures through their actions and relationships to family caregiver participants. I then explore the ways in which family caregivers destabilize assumptions about the authority and power of biomedicine through their daily embodied practice of care and participation in the caregiver classes. Finally, I complicate the practiced refusal of biomedicine on the part of family caregivers by discussing the institutionalization of family.

Chapter Three focuses on the ways in which family caregivers learn how to perform care from medical professionals. Though the classroom is only one way in which caregivers learn the practice of care, the family caregiver classes represent a unique opportunity for medical professionals to actively share their biomedicalized knowledge of care. Through ethnographic accounts of two caregiver class on the subjects of mobility and nutrition, I demonstrate how authority and experience influence the success of knowledge transfer between medical

professionals and caregiver participants. I argue that while it is impossible to teach embodied experiences, the medical professional teachers successfully utilize language as a proxy for experience to share their biomedical understandings of care with the participants.

Chapter Four shares the life histories of two of the caregivers who were involved with the caregiver classes and delves into their experiences with providing care to an aging family member. The two caregivers featured in this chapter have very different experience with caregiving and face different ongoing challenges. Alma has already suffered the loss of both her parents and close aunt, and has since channeled the memory of her experiences as a caregiver into the creation and ongoing maintenance of the caregiver classes. Patty, a former caregiver class participant, recently returned to Hawai‘i after an adulthood abroad to provide care to her now elderly parents. By exploring these women’s unique experiences with caregiving and calling upon anthropological literature on biomedical nostalgia, I explore the options for the future of family caregiving in Hawai‘i.

Chapter Five, the conclusion, summarizes the thesis by demonstrating how the overarching themes of biomedicine as social control, citizenship and autonomy, and the body as the locus of meaning are both omnipresent and in constant flux in relation to end-of-life care in Hawai‘i. I demonstrate end-of-life care as a constantly shifting network of dynamic stakeholders who are both capable of enacting change and subject to sociocultural limitations. Ultimately, I conclude my thesis by providing a summary of recent events in the end-of-life care community and the family caregiver classes.

CHAPTER TWO
CARE, POWER, AND PERFOMATIVITY

Introduction

"You think this is an 'ohana state, but it's not." -Tim, Class Lecturer

Karen, a diabetic double-amputee, stopped showing up for dialysis care one day. Alarmed, the doctor on staff at the dialysis clinic notified Adult Protective Services (APS). The doctor's concern was not unfounded—depending on the severity of their condition, a dialysis patient cannot last long without treatment before they suffer complete kidney failure. The APS agents paid a visit to Karen's home to conduct a wellness check and discuss her absence from treatment; however, she was firm in her refusal of treatment and explained that receiving dialysis care was a continuous burden on her family. Instead of accepting Karen's assertions at face-value, the APS agents were bound to a protocol which required them to confirm her mental 'capacity' to make such serious care-related decisions. If found to be without capacity, the APS agents would then have the power to force Karen to continue dialysis treatment. Over the few days, Karen was assessed by two different psychiatric professionals, who both deemed that Karen was completely within her right mind in making the decision to halt her treatment. Karen never went back to the dialysis clinic to continue treatment, and the APS agents were forced to respect her decision. Within two weeks, Karen was dead.

The aforementioned story—and countless others like it—complicate traditional understandings of biomedical power and authority. Karen's story is just one example of how family caregivers and care recipients in Hawai'i destabilize these structures through the embodied practice of care. Biomedical authority and power structures are maintained through the concept that knowledge is power, and medical professionals embody this position in daily

practice; however, caregivers gain knowledge through embodied experience and exercise individual agency in their care-related decision-making. Karen made the decision to refuse the services of the dialysis clinic, medical doctors, and Adult Protective Services agents based on her embodied experience providing and receiving home-based care.

In the following chapter, I will demonstrate how these individual expressions of care-related agency disrupt Foucauldian notions of power and the biomedicalized, professionalized practice of care. First, I provide a brief discussion of Michel Foucault's concepts of power, including governmentality and surveillance, as they relate to the biomedicalized practice of care in Hawai'i. Foucauldian notions of power and biomedicalization have been the focus of much of modern medical anthropological research, but such theories are prone to fall apart in contemporary practice and in colonized environments. Next, I demonstrate how the various professionals whom I observed and interviewed embody Foucauldian notions of power and uphold this structure in daily practice. Finally, I provide more examples of how caregivers and care recipients—like Karen—disrupt and destabilize Foucauldian notions of power and the biomedicalized practice of care through their own embodied experiences to critique current medical anthropological understandings.

Professionals in Daily Practice

Early on a Saturday morning, coffee in hand, I prepared the consent forms and note-taking materials necessary for my first attendance in one of the caregiver classes as a bona fide researcher. Since I had not yet been invited to help set-up the room, I felt pressured to busy myself amongst the administrators preparing for the arrival of the participants. As I fumbled with the papers in my backpack, I could barely contain my surprise when one of the hospital

administrators and Tim, the lecturer, gravitated towards me to casually chat about work over the past week[1]. Tim explained how he had given the same presentation at a medical school the previous day, addressing hundreds of nursing, medical, and pharmacy students; however, he was more excited to present to the caregivers. While the medical students are forced to attend Tim's lecture as one of many which make up their formalized education into the elite world of medicine, the family caregivers who attend local caregiver classes are closer to the on-the-ground practice of care.

Tim[2] was one of the first professionals I was introduced to during my fieldwork. With an intimidating gaze and militaristic stance, it came as no surprise to me that Tim had worked with Child Protective Services and Adult Protective Services in Hawai'i nearly his entire career. Now a high-ranking administrator, he had worked as a field agent for many years. Through our conversations, I found Tim's career of dealing with the grim reality of abuse to be evident in his no-nonsense demeanor and cynical humor, which also pervaded every aspect of his presentation style. Similar to many of the other professionals I met over the course of my fieldwork, Tim frequently attributed the shortcomings of caregiving to systemic failure, and the majority of the explanations for these systemic problems were discursively tied to Hawai'i as an island state. Rather than exploring the plethora of socioeconomic, historical, and cultural reasons for particular problems faced by the families and professionals involved in end-of-life care, Tim was quick to explain all negative experiences as part of one interconnected problem stemming from geographical distance from the United States mainland.

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[1] Tim also discussed the case of a plane that arrived at Daniel K. Inouye International Airport from an East Asian country with a confused, elderly individual on-board, which required his investigation. The practice of sending family members with dementia to the United States via airplane seems to be a common way of avoiding the responsibility of caregiving.

[2] All names have been replaced with pseudonyms to protect the identity of my informants.

The first way in which Tim attributed the daily struggles of his job to the geography of Hawai‘i was the overwhelming caseload of the understaffed Adult Protective Services. Recent changes to federal legislation changed the category of individuals protected by Adult Protective Services from “elder abuse” to “vulnerable adults,” which incorporates the eighteen to sixty-five year-old demographic of individuals who previously fell through cracks in the legislation. The average agent now receives four cases per week, which Tim believes is a larger commitment than can be properly investigated within that time. Tim elaborated that the burden is exacerbated by the fact that the Adult Protective Services office on O‘ahu manages the cases from all of the Hawaiian Islands, which proves difficult when agents are unfamiliar with one of the outer islands or cannot reach the reported location due to financial or logistical barriers.

Tim further attributed the overwhelming case load to misconceptions and stereotypes about the people who live in Hawai‘i. The majority of Adult Protective Services cases in Hawai‘i are self-neglect, which he discursively linked to the common assumption that Hawai‘i is an ‘ohana, or family-oriented, place. Tim asserted that “you would be surprised how many people here have no one,” and that the resulting reliance on extended family to provide care often results in elder abuse. Tim’s assertive commentary on contemporary Hawaiian culture was met with confusion, discomfort, and a few awkward chuckles. While he acknowledged the bureaucratic shortcomings in the Adult Protective Services’ ability to take on such a steep case-load, he failed to recognize how the economic realities of family caregivers influence the manifestation of ‘family’ in Hawai‘i. As I will continue to elucidate, the decision to pursue (or not to pursue) certain pathways to end-of-life care has little bearing on how much an individual cares about their family; rather, their actions are necessarily informed by the power inequalities and economic realities of living in one of the most expensive states in the United States of America.

In addition to Adult Protective Services and other government departments, Tim noted that professional facilities are overwhelmed, which further contributes to cases of caregiver neglect. "Nursing facilities are severely understaffed" and professional caregiver burnout results in even more work for Adult Protective Services and other end-of-life care services. Here, Tim has highlighted a conundrum that plagues family caregivers. While family plays an undeniably important role, the decision to provide care within the home is heavily influenced by the lack of available care providers and the economic burden of professional facilities. Foster homes can only accept three care recipients at a time, and the availability of privately paying clients from the upper echelons of society allows care homes to be "so picky…they can charge anything if the client will pay it." A Foster Home can house three individuals, the first of which must pay through Medicaid or Medicare; however, the second bed can be filled by either a Medicaid or Medicare client or by a private pay client. Oftentimes, Foster Homes in Hawai'i stop taking clients after finding a private pay client and never fill the third bed. The Foster Home owners can then wait for the first client to die, keeping only the private pay patient without providing more care at a fraction of the income received from a Medicaid patient in comparison to a private pay patient. The persistence of this practice perpetuates the overwhelmed state of end-of-life services in Hawai'i.

Finally, Tim spoke at length about the inner-workings of decision-making negotiation between professionals, caregivers, and care recipients. Capacity, or decision-making capacity, refers to whether or not an individual is deemed to be well enough to make serious, end-of-life decisions for themselves. The responsibility of deciding whether or not an individual has the right to make decisions, such as denying care, falls upon many layers of the bureaucratic structure of biomedical professionals. In order to determine the decision-making capacity of an

individual, Adult Protective Services must call in a psychiatrist to assess the individual; nurses and other lower-ranking medical professionals are not permitted to perform the assessment. Furthermore, the statement of impaired capacity must be confirmed and signed by the individual's attending physician before Adult Protective Services or other professionals can act.

Upholding the Structure

Foucauldian notions of power intersect with the practice of care and the processes of medicalization and, now, biomedicalization by accounting for the transfer of medical responsibility to the individual. Medical interventions—including pharmaceuticals, technologies, or other life-extending treatments—are not always administered by medical professionals in a hospital setting. Instead, the biomedicalized system expects individuals to implement self-surveillance and self-regulation to practice these interventions independently (Clarke et. al. 2003; Foucault 1988). Here, Foucault's concept of governmentality is particularly important. Governmentality is "used to refer to particular kinds of power often guided by expert knowledges that seek to monitor, observe, measure, and normalize individuals and populations" (Clarke et. al. 2003:165). Medical professionals, functioning as experts, instruct other professionals and home caregivers how to best practice care with the expectation that the professionals and caregivers will comply. The medical gaze transforms itself into a mechanism of surveillance which works to enforce compliance beyond the clinic and into the home (Clarke et. al. 2003; Foucault 1975, 1988).

Biomedicalization, then, involves the "commodification of health, the elaboration of risk and surveillance, and innovative clinical application of drugs, diagnostic tests, and treatment procedures" (Clarke et. al. 2003:165). In relation to end-of-life care, biomedicalization broadly

influences the ways in which life spans are extended and the occurrence of death predominantly in "hospitals or other institutions under the control of doctors and nurses" (Field 1996:255-256). More specifically, biomedicalization has resulted in the development and staffing of professional facilities which practice care and administer treatment in accordance with the standards developed and promoted by hospitals (Buch 2015; Field 1996). Specialized facilities transform the practice of care into a commodity which must be paid for, or at the very least learned through the caregiver classes hosted by affiliated professionals.

Care is further biomedicalized as the responsibility to comply with medical treatment and technologies is placed on the individual and enforced through self-governing and self-surveillance. While doctors develop these treatments and interventions, other medical professionals and, oftentimes, untrained family members are responsible for ensuring their application. A manifestation of this can be seen when Tim talked about his desire to address caregivers rather than the students at a medical school. In comparison to a captive audience of medical school students, the home caregivers utilize caregiving skills on a daily basis and seek out the class of their own accord as a measure of self-regulation to meet a standard set by biomedicalization, creating a more direct line of influence between Tim and the actual biomedicalized implementation of care. Clarke et. al. theorize that "in practice, the forces of biomedicalization are at once furthered, revisited, mediated, and ignored as varying levels of personnel respond to their constraints and make their own pragmatic negotiations within the institutions and in the situations in which they must act" (2003:166). The implementation of care-related treatments is subject to financial, geographic, and legislative factors, and individuals are forced to independently make decisions regarding the practice of care. However, if Foucauldian notions of power are effective in controlling bodies in conjunction with the process

of biomedicalization, then we should expect to see medical professionals and family caregivers in Hawai‘i practicing care accordingly.

Power within much of the end-of-life care structure manifests differently from Foucault's initial theorizations about the clinic (Foucault 1975; Goffman 1961). As previously mentioned, constraints and limitations force social actors at various levels of the bureaucracy to navigate care in novel ways (Clarke et. al. 2003). While medical doctors have the benefit of prestige and a high level of education, they remain largely absent from the conversations about the practice of care among family caregivers and on-the-ground professionals. Doctors and psychiatrists remain the authority on providing diagnoses, yet they have very little influence on the implementation of care outside of the hospital or clinic. Other professionals and caregivers have the embodied experience of end-of-life care, coming face-to-face with abuse and exploitation. Professionals, then, can enact power over other professionals or caregivers and develop hierarchies outside of the authoritative "gaze" in order to navigate their roles (Foucault 1975).

The forces of biomedicalization and Foucauldian notions of power act in conjunction upon the practice of care. At the individual level, both professionals and family caregivers are expected to practice care in accordance with the regulations and instructions set forth by doctors through self-surveillance and self-regulation. As a complication of existing in capitalist society, individuals are often faced with significant financial, geographic, and cultural barriers to the biomedicalized practice of care in Hawai‘i. Despite these limitations, professionals from the caregiver classes were able to successfully navigate systemic barriers to care and function within the theorized parameters.

In describing the difficulties faced by Adult Protective Services, Tim invoked the geography of blame, a concept first theorized by Paul Farmer, a Harvard-trained medical doctor

and anthropologist. Farmer applied the theoretical concept of a geography of blame to the United States' accusation that Haiti was the source of AIDS in North America in his book *AIDS and Accusation: Haiti and the Geography of Blame* (1992). Charles L. Briggs (2004) similarly invoked a geography of blame in his research on how the cholera outbreak in Venezuela disproportionately and devastatingly affected indigenous peoples living in the Orinoco Delta area. In both the islands of Hawai'i and Haiti, despite unique cultures and histories, geography of blame is clearly evident in scenarios where blame is cast on geographic space rather than social factors. Family caregivers are quick to accept these justifications and ignore other reasons for problems within the end-of-life system of Hawai'i, but not because they unanimously buy into the idea of geographic blame. The authority of professionals, including doctors, who continue to reference geography in relation to their challenges and shortcomings forces the majority of caregivers to accept this justification. In truth, only the complications faced by professionals are ever addressed in both the caregiver classes and the 'geography of blame' theory, with little concern for the qualms or difficulties of family caregivers (Farmer 1992).

Despite these systemic challenges, Tim still acts in accordance with how we would expect a professional to act given a biomedicalized model of care and Foucauldian notions of power. Geography and culture present as the predominant problems in end-of-life care, according to Tim, because of biomedicalization, which alters the way contemporary society thinks about health. One result of this change is that even family caregivers feel a pressure to professionalize, creating an opportunity for people like Tim to reinforce biomedicalized norms of care down the hierarchy. This also reinforces the necessity to participate in self-surveillance and self-regulation, as the locus of power over care is tangibly closer to the caregivers than when it was located with the doctors. Furthermore, the biomedicalized system of care practiced

throughout the United States and the West was not developed with the island state of Hawai‘i in mind. A successful biomedical system requires colonial infrastructure in place, including transportation, legislation, facilities, equipment, a capitalist insurance, and most importantly, education and training for those inducted into the system. Culture, too, has resisted biomedicalization within the context of Hawai‘i, where a large percentage of the population are recent immigrants to the United States and there is an on-going cultural renaissance to settler colonialism among indigenous Hawaiians. The diverse population of Hawai‘i reflects its history of imperialism and displacement; therefore, a biomedical approach to care which fails to incorporate or acknowledge other ways of knowing about care actively deprives the peoples of Hawai‘i of autonomy over the practice of care.

A second example of how Tim upholds Foucauldian notions of power can be demonstrated through the ways in which professionals interact with the biomedical category of capacity. The ability of medical professionals to judge whether or not an individual has decision-making capacity connects to the large body of anthropological literature on personhood. Anthropological theory understands personhood as something which is socially produced. The social production of personhood can be defined as the ways in which personhood is negotiated—both granted and revoked—through social processes. Beth A. Conklin and Lynn M. Morgan have demonstrated how “concepts of personhood are contingent on the social meanings given to bodies…and, in turn, on how body imageries are used to create and transform social relationships” (1996:657). Ritual is the vehicle through which these social meanings are navigated, and the failure to complete an end-of-life ritual can complicate the personhood status of an individual in the minds of the living, resulting in psychological distress (Conklin and Morgan 1996; Griffin 2012; Hertz 1960). For example, diseases such as dementia complicate the

normalized, ritual trajectory of aging from able-bodied to senescence, and result in the premature revocation of personhood and individual agency (Gjødsbøl et. al. 2017; Kaufman and Morgan 2005). Through diagnosis and treatment doctors are able to exert control over this process, thereby influencing the social aspects of death. Therefore, the process of determining decision-making capacity—essentially the personhood of an individual—highlights one of the many challenges which complicate the biomedicalized role of professionals. By keeping authority limited to the upper echelons of the medical field—a status which requires the most education and resources—doctors uphold the Foucauldian concepts of governmentality and biopower; however, the stipulation suggested by Clarke et. al. (2003) also stands true. Doctors have the power to access the language of biomedicine, utilize biomedical technologies, *and* the authority to command others into action. Adult Protective Services and the Hawai‘i State Police have the power to encourage individuals to comply, but are unable to make commentary on an individual's decision-making capacity.

The Position of Caregivers

In the United States, the federal definition of a 'designated primary caregiver' is any individual over the age of eighteen who is either the care recipient's "spouse, son, daughter, parent, step-family member, or extended family member; or someone who lives with [them] full-time or will do so if designated" (Legal Information Institute 2015). However, this definition applies specifically to veterans under the auspices of the Veteran's Administration, a government organization. The absence of standardized federal legislation creates an ambiguous role for family caregivers outside of similar organizational definitions, and errs on the side of protecting institutional interests rather than the economic and social realities of individuals. In this way, the

federal government creates a 'state of exception' in which caregivers and their care recipients exist in a space outside of explicit legislation (Gupta 2012). This is not to say that more legislation should be introduced to govern the realm of home-based care; rather, it aims to highlight that caregivers are subjected to the application of legislation not explicitly created for providing care in the home. However, legislation does exist to dictate who can complete certain paperwork or what constitutes as abuse, ensuring that the system does not need to order certain individuals to perform care as long as the role of caregiver is filled by someone. Federal legislation leaves much of the control over managing family caregivers to state legislation; however, both federal and state legislation are difficult for caregivers to navigate and utilize effectively.

According to a 2011 study conducted by the American Association of Retired Persons, "Hawai'i ranks low (41st) in the country in terms of single point of entry functionality which indicates that older residents and the people caring for them may have great difficulty navigating the long-term care system," of which legislation is one component. Many of the caregivers and professionals who I spoke with over the course of my fieldwork confirmed this analysis, and complained about the difficulty of effective communication, navigation of services, and abiding by obscure legislation or health insurance rules. The situation in Hawai'i has been made even more complex by the creation of new legislation targeted towards providing family caregivers with financial compensation for the time spent caring for a loved one. The Kūpuna Caregiver Act 102 (*kūpuna*: elder) was passed in 2017 and provides compensation to family caregivers through a stipend. While the initial stipend is $70 per day, advocates hope to increase the budget in years to come. In addition, "the legislation recognizes that many Hawaiian families prefer to have their parents and grandparents at home, rather than in a nursing home or assisted living facility"

(Towey 2017). While many legislators and advocates hope that the Kūpuna Caregiver Act 102 will pave the way for better legislation and potentially serve as a model for other states, not enough time has passed to judge whether or not the Kūpuna Caregiver Act 102 effectively improves the lives of family caregivers and their care recipients.

Documentation plays a crucial role in how family caregivers seem to fulfill their role within the hierarchy, with the documents from different professionals assuming different roles and levels of importance in end-of-life and emergency decision-making processes. While caregivers complete documentation to the best of their abilities in the hopes it will allow them to exact some influence over how end-of-life medical interventions are enacted on their loved ones, oftentimes the hierarchy of documentation is subjective according to the professional. A great social emphasis is placed on the importance of living wills, but emergency responders and medical professionals often prioritize the Physician Order for Life Sustaining Treatment (POLST). While living wills are the family's responsibility to locate and use for decision-making, the POLST provides medical professionals with information regarding specific emergency treatment preferences of terminally ill individuals[3]. Similar to living wills, an Advance Directive explains an individual's care preferences in case of medical emergency. In the event that family members are not present or available, Health Care Power of Attorney (HCPOA) allow another individual to represent your care-related wishes in an emergency situation; however, if documents or a representative are not readily available, medical professionals will mobilize their authority to make their own decisions.

[3] According to one instructor, POLST are most commonly used to specify whether an individual wants cardiopulmonary resuscitation (CPR) or comfort measures only. The instructor specifically told participants that POLST should be updated frequently to reflect what the individual would want in the event that they have little chance of resuming a normal life, since "if you need CPR you actually died of natural causes and are being asked to be brought back to life," because "CPR isn't done on live people."

Hawai‘i state legislation and Adult Protective Services define a caregiver as “any person who has knowingly and willingly assumed, on a part-time or full-time basis, the care, supervision, or physical control of, or who has a legal or contractual duty to care for the health, safety and welfare of a Vulnerable Adult.”[4] The only requirement is that the individual assumes the role. The flexibility of this definition allows for the inclusion of a wide group of people who may or may not share biological relation or place of residence with the care recipient. This definition also incorporates a sense of extended family, given the use of “auntie” to refer to older women within the same community and ideas about ‘ohana. Definitions then carry into the realm of practice, where personal beliefs interact with these definitions to create complicated pictures of end-of-life care in Hawai‘i.

While many of the professionals were very open in their skepticism regarding the importance of ‘family’ in end-of-life care, caregivers painted a very different picture of the lengths a caregiver will go to help an aging family member. Tim is highly skeptical of the concept of fictive kin. Rather than approaching the situation with sympathy, he was harshly critical of individuals who would place their colleagues at risk of losing their job, under the guise of what he believed to be a fake familial relationship. He asserted that “you think this is an ‘ohana state, but it’s not,” because through his subjective experience as an employee of Adult Protective Services, he saw cases of abuse and neglect which he believed to contradict the ideal of family. Tim consistently argued that the role of caregiver is more likely to be motivated by financial exploitation than by familial duty, and was firm in his stance that people assume the role of caregiver to exploit the financial benefits. Keeping a care-recipient at home allows the family caregiver to assume direct control of that individual’s finances and income with very little

[4] This definition comes directly from Tim during the caregiver class.

oversight. Furthermore, from his experience it is not uncommon for those people who send their family member to a care facility to stop sending payments and keep any pension and social security checks for themselves; however, Tim's argument is complicated by advocacy groups and caregivers who claim they are not economically stable enough to provide an adequate level of care. In contrast, of the thirteen caregivers in attendance at one class, ten came to the class to get help for a family member—biological or fictive[5]. Oftentimes, participants travelled a great distance to attend the caregiver classes or were suffering from emotional and financial burdens. Many people over the course of my participant observation engaged in medical tourism[6], coming to Hawai'i for the express purpose of gaining knowledge about caregiving from professionals through the caregiver classes with the intention of taking the knowledge back home. However, these people do represent a privileged demographic who have access to caregiver classes or the knowledge to seek out help early.

In one of the caregiver classes there was a group of four family members—one brother, two sisters, and a cousin. The sisters and cousin were visiting from the mainland United States in order to attend the caregiver class. The cousin had previous experience with his own parents in hospice, and now his family-in-law is going through a similar experience. The siblings' parents are currently in critical care and were given a six month prognosis. They chose to attend the class to aid in their decision-making process regarding whether or not to put their parents in hospice care. The family described how they held a "council of siblings" to provide other distant family members with updates in order to "maintain relationships" even after their parents pass. They

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[5] The remaining three participants, two men and one woman, were professional caregivers who attended the class at the request of their superiors to refresh their memory of certain information. I later discovered that one of the men, Rick, was actually providing care to a former client who had become financially unstable, and had assumed the role of his legal caregiver unknowingly.

[6] The majority of caregivers engaging in medical tourism came from other parts of Oceania, including Okinawa and Tonga. Many expressed the desire to return to their home countries with their newfound caregiving knowledge.

placed an emphasis on questioning how they could get through this experience without ending their family's strong relationship.

Over the course of my research, I also heard many stories of the strategies caregivers use in the home. Oftentimes, caregivers refer to the strategies as "little tricks" they pull on their loved ones to keep them safe and healthy. While not of malicious intent, these "tricks" often take advantage of cognitive or visual impairments of a loved one in order to accomplish a goal. For example, one caregiver shared the story of how their care recipient would frequently attempt to leave the home due to confusion caused by dementia. If given the opportunity, they would walk out the front door of their Honolulu home expecting to see the familiar sights of their childhood home in Hilo. In order to prevent the care recipient from dangerously leaving the home in a confused state, the caregiver discovered they could take advantage of their loved one's poor eyesight. By placing a dark-colored mat in front of the exits to the house, the caregiver was able to "trick" the care recipient into thinking there was a large, unsafe hole in front of the door. As a result, the care recipient was effectively deterred from leaving the house. Other caregivers shared their similar experiences and solutions, including placing matching curtains in front of all doors and windows. The story of these strategies exemplifies my main point: while the institution of family plays an undeniably crucial role in end-of-life care in Hawai‘i, family ultimately imitates the larger institutions which govern it.

Complicating Power

On the surface, family caregivers disrupt the ways in which Foucauldian notions of power and biomedicalization act upon the practice of care in Hawai‘i, contrary to the choices and actions of professionals. While professionals hold the expectation that family caregivers will follow-suit in self-surveillance and self-regulation to practice care in accordance with the

instructions given by medical doctors, instead economic limitations and the institution of family significantly influence the decision-making process in ways which contradict the system described in the chapter thus far. Rather than navigating care in close accordance with biomedicalization like the professionals, family caregivers prioritize home-grown solutions which outwardly manifest as actions subversive to the processes of biomedicalization and Foucauldian power structures. In the following section, I will theorize how caregivers interact with 'family' as an institution which mimics the larger institution of biomedicine and provide examples of how the ways in which caregivers practice care in the home are actually manifestations of Foucauldian biopower (Clarke et. al. 2003; Foucault 1975, 1978).

Caregivers, responsible for implementing and practicing care outside of professional facilities, find themselves at the bottom of the biomedicalized social hierarchy with little room for subversive activity or resistance within the system. Even acts which form a daily part of providing care may require official authorization from a doctor. According to state legislation, physical abuse includes any "improper physical restraints," and even the installation of bedrails or locking a door requires permission from a medical professional. Furthermore, individuals who have negative experiences with the end-of-life care system, such as an unfriendly staff member at a nursing facility, are often afraid of retaliation due to the power wielded by professionals higher in the system; therefore, in this way, they practice self-regulation and self-surveillance.

By rejecting both the professionals' negative conceptions of family and recommendations for the practice of care and end-of-life decision-making, caregivers are rejecting essential parts of how care is practiced by professionals in Hawai'i. Mary-Jo DelVecchio theorized that rather than a one-sided relationship between medical professionals, patients, and biotechnology, "patients and their clinicians embrace, even as they are embraced by, biotechnology and how American

medical culture generates enthusiasm for experimental clinical science" (2007:367). This 'biotechnical embrace' is evident in the family caregivers' desire to attend and actively participate in the family caregiver classes (DelVecchio Good 2007). By attending the classes and taking their care recipient to doctor appointments, family caregivers search for hope in biomedicine, biomedical technologies, and biomedical treatments. However, what begins as an embrace is deteriorated through the embodied experience of providing care within the confines of the home. As family caregivers come head-to-head with aspects of biomedical care which challenge their cultural beliefs and economic capabilities, they become disillusioned with the degree to which biomedicine can offer solutions to the everyday challenges which accompany providing care to a loved one within the home. Tension within contemporary end-of-life care stems from a breakdown of the delineation between public and private as the (potentially unwanted) forces of biomedicalization continue encroach on the home despite a breakdown of the 'embrace.'

The deterioration of the biotechnical embrace does not represent a larger rejection of Foucauldian notions of power and biomedicalization (Clarke et. al. 2003; DelVecchio Good 2007). Caregivers may complicate Foucauldian notions of power and the medical gaze because while they are practitioners of care, they exist outside of the medical language (Foucault 1975). The medical gaze cannot exert power over individuals and bodies if the language cannot be translated to non-professional caregivers. While they utilize medical technologies such as pharmaceuticals, wheelchairs, and CPAP (continuous positive airway pressure) machines, they are unable to access those technologies which provide "truths" and constitute the body in the eyes of medical professionals (Joyce 2008:61). By practicing care in the home and ignoring the recommendations of medical professionals in favor of their own care strategies, family

caregivers are removing bodies from the direct control of the institution of biomedicine over individuals (Foucault 1978). The bodies of care recipients now exist outside of biomedicalized institutions and within the home, where caregivers feel removed from the pressures of surveillance and societal governance; however, I argue that caregivers and care recipients then become accountable to family as an institution as a form of medical autonomy. Obligation to the cultural concept of family creates this institution, in which caregivers are afforded the power to control the bodies of care recipients. By taking a closer look into the lived experiences of caregivers we can understand that in the home the overarching systems of power and biomedicalization often go ignored in favor of strategies which achieve the best result in line with economic limitations which inform the institution of family. Therefore, the aforementioned "little tricks" are a way of exercising autonomy, biopower, and controlling the bodies of care recipients. Through the caregivers, the institution of family has control over bodies through an intimate understanding of the practice of care. Just as biomedicalization gives medical professionals control over bodies in the medical institution, family gives caregivers control over bodies in the familial home.

CHAPTER THREE
LEARNING CARE

Introduction

"Locals will tell you to brown the meat." -Leilani, Caregiver

I arrived at the hospital approximately half an hour early, and for the very first time I was asked to help set-up the classroom. Dorothy, a retired registered dietitian and the lecturer for that day's class, had prepared several demonstrations and an interactive taste test. I helped to pour samples of five different nutritional supplements into small cups: Ensure® Original, Ensure® High Protein, Ensure® Clear, Boost® Original, and an organic alternative. Dorothy explained that these taste tests allow family caregivers to sample the supplements before committing to a purchase at the grocery store; furthermore, the caregiver's decision determines what their loved one will be drinking for a long period of time. While I did not notice abject reactions to any of the samples, I did notice some samples received a more positive reaction than others. Ensure® Clear received an overwhelmingly positive reaction, and was praised by both Dorothy and many of the participants for its similarity to fruit juice. The other samples feature a milk-like consistency which was off-putting to the caregiver participants who are predominantly of Asian-descent and, therefore, largely lactose-intolerant. Dorothy described how you can "sneak [the supplements] into all kinds of stuff" to trick care recipients into drinking them, and recommended mixing the vanilla-flavored supplements into poi.

Through the aforementioned taste test, Dorothy is attempting to teach the caregiver participants how to experience the process of providing care through a representation—or simulation—of care; however, the experience of observing or participating in a simulation is not the same as the lived, embodied experience of actually providing care. Through the embodied

practice of care, family caregivers undergo a transformation in which their bodies become "the subject of culture" rather than "an object to be studied in relation to culture" (Csordas 1990:5). The embodied, phenomenological experience of providing care in the home—feeding, bathing, transporting, among other acts—cannot be recreated within the confines of a classroom. Instead, language is used as a proxy for experience to allow medical professionals to simulate events that occur in the daily life of a family caregiver. The caregiver classes' strategy falls short as the caregivers' experiences disillusions them to the sterile examples provided in the classroom. What is accomplished through the simulations provided in the caregiver classes, however, is the maintenance of bureaucratic categories by sharing recommendations for courses of action related to care.

Since the experiential knowledge-based caregiver classes continue to be offered, they must successfully serve another purpose. In failing to teach something which cannot be taught, caregiver class lecturers help to maintain bureaucratic categories and the cultural construct of medical expertise. As previously described, a core component of the process of medicalization was the "professionalization and specialization of medicine" (Clarke et. al. 2003:163). Contemporary biomedicine, then, must foster a reliance on medical professionals and maintain this distinction through barriers to medical knowledge. In turn, the preservation of biomedical expertise serves a variety of political purposes, namely legal accountability for malpractice or bodily harm.

Through two ethnographic case studies, I will demonstrate how the caregiver classes both failed to teach experiential knowledge and succeeded in upholding bureaucratic categories. Furthermore, I will show how the participants refuted the lecturer's biomedical knowledge with their own understandings of care garnered through embodied practice. The teachers of the

experience-focused classes were medical professionals and administrators from a variety of backgrounds. Out of the two course sessions discussed in this chapter, there were three teachers: (1) Tyler is a Doctor of Physical Therapy who practices on the island of Oʻahu, who was joined by (2) Jade, a practicing physical therapist from another local hospital, and (3) Dorothy is a retired dietitian and nutrition specialist who now volunteers through various hospital-based programs for end-of-life care. In comparison to the predominantly male professionals described in the previous chapter, two of these three caregiver class instructors are female; however, they all occupy similarly prestigious positions. Through rhetoric and experience they distanced themselves from the caregiver attendees, and placed themselves higher in the end-of-life care hierarchy by assuming authority over knowledge about care. The first case study examines how medical professionals attempted to teach the experience of care to caregiver class participants through a case study of a caregiver class focused on mobility training. The second case study analyzes the events of the diet and nutrition-focused class, which represented the most strongly contested experience-based knowledge between the medical professional teacher and caregiver participants.

Mobility

When I walked into the classroom one evening, I immediately noticed a rather unique set-up. Rather than the typical front-facing rows of tables, all of the tables were set at diagonal angles like a spread-out chevron to create a large open space between the two rows. As usual, I set down my backpack in the front right of the room and greeted people as they walked into the classroom. Alma started the caregiver class by explaining how the volunteer trainers for this class session, Tyler and Jade, generously took their free time after work to be there. The

unspoken expectation was not for medical professionals to actively share this information as a part of their profession; rather, the participants were expected to be grateful for the generosity of the physical therapists and go out of their way to find the caregiver classes in order to be provided with hands-on training.

After a casual introduction, Tyler explained that within geriatric settings, physical therapy is more concerned with movement, while occupational therapy deals with everyday tasks such as bathing and cooking. Therefore, Tyler covered topics during the class such as bed mobility, general transfers, shower chairs, car transfers, and walking with a cane or walker. His explanations, manner of speaking, and terminology over the course of the class were extremely technical. For example, within a larger explanation of transfers, he stated that caregivers should use a "countdown system," to which one of the caregiver participants immediately asked "what is a countdown system?"[7] At another point, he used the term "AFO," to which another participant asked "what's an AFO?"[8] Occasionally, Tyler would explain difficult terminology without prompting from the participants. For example, he explained that 'supine' is "what we call laying down flat in PT terms." As a Doctor of Physical Therapy, Tyler took advantage of the prestigious language and authority of medical professionals which serves as an effective gatekeeping strategy for medical knowledge. At the same time, his rhetoric was inclusive of and geared towards family caregivers. In all of his explanations, Tyler would refer to the "loved one" or "family member," rather than "patient" or "client."

Tyler began the lecture-portion of the class with "body mechanics," which he explained as "things to do; not to do" in regards to the caregiver's own body movements. He emphasized

[7] A "countdown system" is a tactic used by caregivers and care recipients when moving, in which both individuals count down from ten to one to prepare to move in unison.
[8] An "AFO," or ankle foot orthosis, is a device used to stabilize a weak ankle.

that body mechanics are the "main premise of what we're working on," and included points like using your legs your legs to lift and keeping the person or object close to your own body when lifting. The focus of the techniques covered in the class was 'minimal assistance,' whereas 'maximum assistance' would require the aid of two or more people within a professional care facility. The rhetorical strategy of allocating medical professionals the authority to access methods of care unavailable to family caregivers in the home was emphasized throughout the mobility class.

Tyler then described the "principles of transferring." He emphasized that the caregiver class participants would get hands-on experience during the "practical portion" of the course, and a better look at hand placements. When explaining how to move someone around who is in a bed, Tyler stressed not to pull on their arms because it could cause shoulder dislocation. Rick, one of the participants who had significant experience with providing care to bedridden individuals, asked "wouldn't a gait belt be better?" Tyler explained that because his hands are located on the care recipient's knees and shoulders and the gait belt is located on the pivot point, the gait belt strategy would be less effective. This response was met with some confusion, and became the focus of hands-on experimentation at the end of the class. Without a visual representation, much of the lecture was difficult to conceptualize for both myself and the caregiver participants. At this moment, however, Rick continued to assert that his patient would not be able to get into the position Tyler described as the proper way to move someone in a bed, and explained several real-life scenarios from his own caregiving experience in which the medically prescribed technique would not work.

After a brief description of 'sit-to-stand transfers,' Tyler demonstrated some 'standing pivot' transfers using a wheelchair provided by the hospital. He stressed that the wheelchair

needs to be at a ninety degree angle to the target, or "as close as you can," and showed how the wheelchair armrest could be removed to facilitate the movement. Immediately, several of the caregiver participants expressed their shock at the removable armrest, and Patty suggested that the wheelchair must be the "deluxe" option. For many of the participants, this model of wheelchair was too expensive to represent a realistic economic option. Furthermore, Rick and several other participants expressed their concern about the ability to conduct this maneuver with "dead weight," especially when the care recipient is overweight. Tyler explained that this scenario would be the proper time to use a gait belt (in comparison to the aforementioned bed transfer), and demonstrated several styles of gait belt.[9] He showed both canvas and nylon options, but explained that the nylon is easier to clean, albeit more expensive. I noticed several caregiver class participants, including Patty, scanning the Amazon listings for gait belts on their smartphones during this conversation, presumably to find the best options.

By this point, the conversation had completely diverged from the presentation slides and participants began to ask rapid-fire questions about the medically 'correct' way to perform various maneuvers. Many different conversations were being carried on all at once, and Tyler began discussing the pros and cons of transport wheelchairs versus manual wheelchairs with one of the participants who was still confused what wheelchair they should purchase to have a detachable armrest, and why there were so many different wheelchair options in the first place. Rick interrupted and asked about the best wheelchair for his "client who wanted to be very independent but had a stroke" and frequently forgot to lock the brakes on the wheelchair. Tyler suggested that he "tape a sign on the wheelchair," but Rick lamented that "*every* part of the day you have to remind them." Oftentimes, the caregivers had already attempted to implement the

[9] A gait belt is a belt with a simple clasp which uses a metal grip to stay locked in place, and can be used as a place for the caregiver to easily hold onto the individual.

medical professional's first, and even second, recommendation, suggesting that the medical professionals were ignorant to the caregivers' needs or to the diversity of scenarios in which family caregivers may find themselves.

Throughout the remainder of the lecture, the caregiver participants continued to contest the information and techniques offered by the physical therapists, and oftentimes shared their own experiences and solutions. For example, Tyler introduced a device called a "seat spinner" for car transfers, which Alma explained can be purchased online; however, one participant interjected that a high quality plastic grocery or trash bag can work just as well. Rather than paying for an expensive device, many other participants confirmed that a plastic bag is easy to store in the car for quick transfers.

Tyler decided the lecture portion of the class was complete and all of the participants were split into two groups for hands-on activities and demonstrations. Everyone was ushered down a narrow hallway into another room labeled "surgery classroom," which was filled with a variety of props including hospital beds, wheelchairs, commodes, and shower stools. Each groups spent twenty minutes at each station, and then switched. The first session my group participated in was for wheelchair transfers, and as we waited for Tyler to set up the props the participants in my group had a conversation about how insurance will not cover the cost of many of the professionally-recommended devices, yet home renovations are not always possible and professional care is even more inaccessible.

Tyler then called upon me to be the visual example of the wheelchair to walker transfer. With the gait belt fastened onto my waist, Tyler moved me in and out of the wheelchair to the walker by scooting me forwards with one hand on the back of the gait belt near the base of my spine and leaning me forwards. The process was not uncomfortable, but I certainly noticed how

strong Tyler needed to be in order to move my dead weight forwards using one arm on the gait belt. He also explained that a walker could be held loosely in the hand of the care recipient during any kind of transfer for additional stability. Patty excitedly mentioned that her father " has one of those Asian bamboo ones with the wrist bands…" to which Tyler immediately replied "that's more of a walking stick" rather than a functional, medical walker.

We then moved to the next station, which was a demonstration of bed transfers. The set-up had an actual hospital bed with railing. Jade explained that the most important part of this transfer is to "set them up for success; have them more or less in a good position" closer to the head of the bed. She demonstrated a series of techniques, but I had a difficult time seeing the demonstration because all of the other participants began eagerly crowding around the bed. When laying the pseudo-care recipient down, Jade stressed that they should go down towards their stronger side and onto their elbow. If the care recipient ended up too low in the bed, a nylon draw sheet positioned under the care recipient could be utilized to help scoot them towards the head of the bed. Patty asked "is that [nylon] okay? Does it breathe?" Jade shrugged, and replied "yeah…I think so," indicating a lack of personal experience with the product she was promoting to the family caregivers. Another participant leaned over to Patty and half-heartedly whispered "I wouldn't use that" and scrunched her face up in a look of disgust and distain for the nylon sheet.

Upon noticing Jade's hand placement on the volunteer's shoulder blade, another participant anxiously asked "what happens if at one time they broke their shoulder?" Jade explained that her hand was in the ideal position closer to the center of the back, rather than anywhere that would cause a person pain. However, another participant suggested "you could also pull the sheet," and demonstrated how to roll a care recipient by pulling on the sheet from the opposite side of the bed. This suggestion was met with overwhelmingly positive responses

from the other participants, and represented a tactic many of them could use or had previously employed.

Patty, who had volunteered to role-play the care recipient in the simulation, explained that the care recipient was "gonna have to have a little upper body strength" to do any of those maneuvers, reflecting upon the phenomenological experience of going through the actions. She also noted multiple times that the nylon was "really slippery" and feigned accidentally sliding out of the bed, suggesting that she was still uncertain about the usefulness and overall safety of the device in comparison with its price. The participants then assumed control over the simulation, and spent some time pulling the nylon off the bed and testing the difference. Patty noted that without the nylon there was more grip to the bed, but did not indicate whether she perceived this as good or bad.

The final component of the class was a demonstration of car transfers, which required everyone to move downstairs to the basement parking garage. All of the participants gathered around a regular, four-door sedan, and Tyler opened the passenger-side door to demonstrate the transfer. Leather seats provided an easier slide, so a seat spinner or plastic bag was recommended for cloth interior. While shouting over the ear-splitting siren of an ambulance, he demonstrated how the care recipient should lean back, turn into the seat, and then move the seat into a regular sitting position. Several participants lingered to ask the physical therapists questions about the demonstrations, but many other participants shared stories of their own lived experiences on the way out of the building without asking questions or seeking specific advice.

Diet and Nutrition

Of the thirteen participants, many had attended previous caregiver class sessions. First-time participants included a woman who came to the class because she was providing care to her ninety-six year old mother who was diagnosed with dementia, but her mother had spontaneously decided she did not want to eat solid foods; however, she could eat solid foods that she likes, such as hard candies. Carol, a relative of a regular participant, attended the class to gain insight into the care of her ninety year old mother who was diagnosed with diabetes, dysphagia, and Alzheimer's. She began supplementing her mother's diet with calories, and had a lot of experience caring for an individual with dysphagia. Carol was extremely vocal throughout the class, and was willing to speak-up whenever she thought the information provided to caregivers during the class was incorrect, out-of-date, or not applicable to daily life. Another woman, Leilani, was a middle-aged Hawaiian woman who recalled a time when her mother had cancer and only wanted to eat poi[10]. She decided to attend the classes to prepare for the next time she would have to provide care to a loved one.

Dorothy began the class by lamenting about the plethora of conflicting nutritional information available nowadays, and how some things which were once considered "bad" may become "good" again, and vice versa. Therefore, the focus of the class was to teach everyone how to make "healthful and appealing meals" for a loved one, even if "sometimes you have to be tricky; throw some greens in their smoothie." According to Dorothy, common diet-related problems that occur among elderly people include obesity, malnutrition, osteoporosis, cardiovascular disease, diabetes, and cancer. Dorothy discussed the importance of maintaining a healthy body weight, which "depends on the season that they're in." She explained that while it

[10] Poi is a traditional Hawaiian food made from fermented taro root that is pounded into a paste using a large stone pestle.

is okay for younger individuals to be thin, as people age body fat becomes increasingly important. A common problem addressed by Dorothy and confirmed by the participants' stories was the difficulty of convincing a care recipient to eat due to a decreased appetite and metabolism. When a care recipient is refusing to eat, Dorothy explained that it is "important to factor in the social things," difficulties chewing or swallowing, or social deprivation and loneliness. If an individual fails to eat "correctly," they are at a higher risk of falling ill.

Dorothy then turned the conversation towards the importance of water. She explained how sometimes an individual who is not drinking enough water will have a suppressed appetite, in addition to other problems such as dry mouth. In order to avoid these problems, she suggested using juice to dilute water, or giving the care recipient ice chips to stimulate the salivary glands. Furthermore, Dorothy mentioned that "in facilities they measure their in's and out's," meaning professional caregivers measure liquid consumption against urination and defecation to keep track of an individual's health in a manner that can be recorded and analyzed. The importance of this repeated comparison of professionalism can be seen in the ability of care facilities to "quantify things when [the family goes] to the doctor," a technical language which directly translates to power in the biomedical sphere of practice.

For example, care recipients often have special dietary needs which necessitate careful attention to ingredients, consistency, and caloric intake. Dorothy focused specifically on calories, and explained how "when you look at labels, those are based on someone who needs 2,500 calories per day," yet elderly individuals require significantly less. Her recommendation to the family caregivers was to use a smaller plate and "reduce the carbs," because she did not expect them "to be counting calories, that's too hard." A popular example of this strategy can be seen in the United States Food and Drug Administration's mock plates, which are used to help

individuals visualize the idealized plate of half fruits and vegetables, a quarter lean protein, and a quarter whole grain. Here, Dorothy lightheartedly criticized the eating culture in Hawai‘i, lamenting that “it’s half rice, some meat, and a teeny-tiny bit of vegetables.”

One medical problem that many of the caregivers wanted to have addressed was dysphagia. Dysphagia is a condition in which an individual has difficulty swallowing, increasingly the likelihood that liquid could travel down the trachea to the lungs rather than down the esophagus to the stomach. Rick described how his care recipient refuses to drink water and only wants sugary drinks after taking medication despite a long history of diabetes. Carol explained how she learned how to thicken liquids from a speech language pathologist for her mother with dysphagia. These questions and scenarios provided Dorothy with an ideal transition to demonstrations of nutritional supplements and thickening agents as potential solutions to water consumption and nutritional deficiencies. Dorothy demonstrated how water (and other liquids) can be thickened to the consistency of honey using a readily available thickening agent. In a small, clear glass she mixed a spoonful of white powder into water, and then passed the glass around the room. The water had become cloudy and grainy, reminiscent of applesauce or a science experiment gone horribly wrong. Carol interrupted the demonstration, and explained that she uses a different brand of thickening agent due to an off-putting appearance exemplified by the cup of grainy water. She strongly insisted that no one would drink anything thickened using the thickening agent Dorothy had shared, noting that elderly or dying individuals still care about the appearance, texture, and taste of their food.

Finally, Dorothy discussed a few specific diets with the disclaimer that she was about to get “science-y.” She read directly from printed notes, and began to make very wide generalizations about what should or should not be eaten. For example, she said that “they found

that" eating seafood, berries, and walnuts helps to preserve brain health. Free radicals, or "molecules that cause cell damage," should be avoided by restricting the consumption of browned, charred, and fried foods. Many of the participants were frustrated by this information, and pushed back against the notion that traditional or beloved foods have a negative impact on the body. Leilani, an indigenous Hawaiian, ended the conversation with a strong assertion that "locals will tell you to brown the meat," a clear indication that she had no intention of changing her food culture to satisfy the theories of Western scientists.

An Issue of Expertise

While biomedical knowledge about caregiving is necessarily taught through the use of language as a proxy, the caregiver participants' lived experiences with end-of-life care in the home disillusions them to the examples provided within the confines of the classroom. As mentioned at the beginning of this thesis, phenomenology fundamentally involves the body as "the subject of culture," and rather than rather than focusing on the experiences themselves a phenomenological approach explores how events are experienced by the body (Csordas 1990:5). By focusing on embodied experience, I understand "the body as a product of social, cultural, and historic contexts" (Lock 1993:136). By invoking Bourdieu's notion of habitus, or ingrained and inherent ways of knowing the world which are at least in part shaped through social interactions, the caregivers' rejection of the content of the caregiver classes can be understood as failing to capture the social component of providing care within the family home.

For example, during the mobility class Tyler and Jade attempted to teach the caregiver participants about the mechanics of a sit-to-stand wheelchair transfer. While the physical therapists can provide a visual demonstration, or even include a volunteer to perform as a wheelchair-bound individual, the staged example does not function as a stand-in for lived

experience the way encountering it over and over within the context of the home does. Symbolic knowledge regarding the theoretical mechanics of a wheelchair transfer is in fact the only information being conferred by Tyler and Jade in this scenario. In a family caregiver's daily life a variety of other factors come into play which complicate this knowledge and highlight the failure to convey embodied experience. The type of wheelchair used by the caregiver may be different, the physical space in which the transfer occurs could pose new limitations, or the care recipient's unique health conditions could prevent the use of a gait belt. A second ethnographic example is when Dorothy demonstrated the use of thickening agents for participants providing care to an individual suffering from dysphagia. A demonstration of simply adding a particular brand of thickening agent to water fails to encompass both the innovation of caregivers and the entirety of situations which occur when preparing food or drink for a care recipient with difficulty swallowing.

Therefore, the aforementioned examples represent a two-way failure of communication—experience both cannot be taught by the professionals and cannot be learned by the caregiver participants. While the professionals can show caregivers how to do a particular action and provide the accompanying symbolic knowledge, they cannot provide caregivers with the phenomenological experience of providing care. As previously mentioned, the idea of learning an embodied experience in a classroom setting goes against the concept of phenomenology; therefore, caregivers can choose to accept symbolic knowledge from professionals but their own truly embodied experiences may be contraindicative. This is evidenced in the reactions caregiver participants had to the symbolic and pseudo-experiential knowledge of the caregiver class teachers. The participants frequently called upon habitus and their own embodied experiences to refute the knowledges provided to them through the caregiver classes. One example of this

phenomena was when Patty questioned Jade's recommendation of the use of a nylon sheet to facilitate bed transfers. While Jade believed the nylon sheet to be beneficial to her demonstration, Patty's own experiences resulted in a questioning of the nylon sheet's usefulness in practice. The reactions of participants and the ways in which they refute the knowledges of professionals hints to perhaps a deeper purpose to the caregiver classes.

If the experience of providing care cannot be comprehensively taught, and is seemingly refuted by the caregiver participants' own experiences, why do classes focused on this experience-based knowledge continue to be taught and attended? One answer is that in teaching both symbolic and pseudo-experiential knowledge about care to family caregivers, medical professionals reinforce certain categories, such as expertise. I am referring to the expertise of biomedical professionals, in particular. As previously mentioned, the process of medicalization primarily involved the "professionalization and specialization of medicine" in which knowledge about medicine was obscured through specialized language shared only by those initiated into the practice of biomedicine (Clarke et. al. 2003:163; Foucault 1975). Family caregivers require training from medical professionals to employ biomedical technologies such as wheelchairs and dietary supplements. This system of biomedical expertise relies on obscuring the processes of medicine and, more broadly, science. The process briefly manifests in a tangible way when Dorothy describes research on the ideal human diet, to which the family caregivers should attempt to adhere. The "they" in this context can be assumed to be scientists and medical professionals who possess biomedical expertise; however, as Bruno Latour and Steve Woolgar famously demonstrated in their book *Laboratory Life: The Construction of Scientific Facts* (1979), the process of science is subject to the humans who conduct science and is therefore not exempt from error or subjectivity.

The use of specialized language within the caregiver classes is evident in the ways in which Tyler described various physical therapy concepts to the participants. Rather than saying 'to lie on one's back,' Tyler consistently used the jargon equivalent of 'supine.' In this way, language functioned as a gatekeeper to participation in the practice of care at a level of higher expertise. Through the use of biomedical jargon, Tyler and Jade (along with other biomedical professionals) are able to see into and understand the body in ways which are purposefully obscured from the family caregivers. Language, however, is not the only way in which the medical professionals reinforced categories of expertise through their interactions with caregiver participants. These categories are evident in the medical professionals' descriptions of practice. When describing body mechanics, Tyler explained that he was purposefully describing only 'minimal assistance' techniques because 'maximal assistance' is practiced only within professional care facilities by professionals who have the expertise to perform the maneuvers. Another example in which the medical professionals uphold and reinforce categories of expertise is when Dorothy introduced the United States Food and Drug Administration's (USDA) mock plates. While the plate examples are at once an attempt to make biomedical concepts accessible to family caregivers, they also represent an idealized diet created by the United States government which does not reflect the food culture or eating practices of all individuals, including the family caregiver class participants. The USDA plates serve to reinforce an idealized diet proposed by the United States government in conjunction with biomedical officials, with little consideration for the lived realities of individuals throughout the nation. In Japan, white rice is an essential part of many meals, and it can be said that other foods exist only to complement the rice; therefore, how could it be proposed for a Japanese-Hawaiian family to consume only a half cup of brown rice with a meal?

The reinforcement of categories creates dissonance between the biomedical professionals who uphold these categories and the family caregivers whose lived realities and embodied experience conflict with the successful implementation of the recommendations which uphold the categories. The dissonance is realized when caregivers directly contradict or voice their dissent in relation to the professional's recommendations, such as when Carol refused to use the thickening agent or when Patty disliked the nylon sheet. These tools suggest to family caregivers that they lack the expertise needed to perform tasks which are routinely completed by medical professionals. The medical professionals, then, continue to reinforce these bureaucratic categories for an important reason.

In reinforcing bureaucratic, biomedical categories, medical professionals are interacting with larger sociopolitical and economic forces. By preventing family caregivers from practicing certain aspects of care in the home they protect both the expertise of medical professionals, and the medical professionals from the potential legal repercussions of malpractice. The USDA plates provide a clear example of the connections between the recommendations of medical professionals in the caregiver classes and these larger political and economic forces. Dorothy introduced the plates to promote a healthy diet among both the family caregivers and their care recipients. The main implication is that the USDA, who created the plate examples, has scientific authority over an accessible, healthy diet that outweighs knowledge gained through embodied experience. Here, it is important to note that the USDA nutrition recommendations for U.S. residents represent the specific needs of the contemporary U.S. population at large, and should not be taken to represent the complete extent of sustainable dietary pattern variation. According to the USDA nutrition recommendations, a healthy meal is comprised of half a plate of fruits or vegetables, one quarter plate whole grains, and one quarter plate varied protein with an

additional side of low-fat or fat-free dairy. For many family caregivers, what constitutes a ‘plate’ or how a familiar family recipe might fit into the guidelines of ‘health’ can be challenging questions to overcome. For example, the overwhelming preference for white rice among many families who track their lineage to East and Southeast Asia is steeped in historical and socioeconomic implications, and it would be difficult to convince someone who learned this preference through lifelong embodiment to transition to unpolished brown rice. When confronted with the daunting challenges of caregiving, however, family caregivers are reliant on the authority of the USDA to make decisions regarding their care recipient’s diet lest they be labeled as a bad caregiver.

A second implication is that the scientific authority of the U.S. government is not biased by ulterior economic motivations. However, through the promotion of certain dietary recommendations the USDA has the potential to influence agricultural production and commercial manufacturing. The recommendation of including a low-fat or non-fat dairy product with each meal, for example, can influence consumer purchases and push the dairy industry to develop more low-fat or dairy-free alternatives for predominantly lactose intolerant populations, such as Hawai‘i. Therefore, it can be understood that through successfully conveying biomedical recommendations, medical professionals uphold bureaucratic categories and have the potential to influence larger socioeconomic forces by encouraging caregivers to change their habits and diets.

CHAPTER FOUR
AGENCY, AUTONOMY, AND NOSTALGIA

Introduction

I take [my parents] to the doctor and I'm like well this doctor said this and oh what did he say…you're talking to a layman here…I can tell you this is what he said but what it means really? And the bigger picture and all that…do I look like I get $500,000 per year? Did I go to med[ical] school?
- Patty

Through our conversations, I learned that both of my key informants feel a close connection to how their families arrived in Hawai'i. For many people who live in Hawai'i, the story of who their relatives are and where they came from is well-memorized and even better documented. Both Alma and Patty reflected on their family histories with great pride and looked to the struggles of their parents and grandparents as a source of strength and inspiration; however, they were also cognizant that their family histories resulted in marginalization and challenges to end-of-life care. Given the settler colonial history of Hawai'i, decolonial theory provides a framework through which to begin to better understand these experiences. By briefly exploring this body of literature, I believe both medical professionals and family caregivers can begin to reconcile their differences through a mutual understanding of community and family-driven motivations for providing care in seemingly noncompliant ways.

The preceding chapters have explored the perspectives and lived experiences of medical and administrative professionals as understood through the lens of the caregiver classes hosted by a local hospital; however, the lives of family caregivers outside the scope of these classes has been largely absent from this discussion. In the following chapter, I will delve into the life histories and lived experiences of family caregivers in Honolulu, Hawai'i. I will begin by sharing the stories of two family caregivers—Alma, who has already acted as caregiver to both parents

and a close aunt, and Patty, who returned to Honolulu to begin the journey of caring for her aging parents—as they were relayed to me through semi-structured interviews. The stories of two caregivers, one who is just beginning to assume the role and one who has been living in the role for many years, capture just some of the diverse experiences and struggles felt by those who engage in end-of-life care.

One important group who was largely absent from the caregiver classes and this research are the Kanaka Maoli, or indigenous Hawaiians, who are disproportionately affected by settler colonialism and health disparities. Since I did not encounter this important demographic during the course of my fieldwork, their experiences are necessarily left out of this ethnography; however, important research has been and continues to be conducted on the unique challenges faced by indigenous Hawaiians in relation to health and end-of-life care (McMullin 2010). Furthermore, family caregivers come from different backgrounds and care for loved ones with different medical conditions; therefore, I take care not to conflate their lived experiences and note that family caregivers to not always share the same needs and concerns. There exists a need to acknowledge the diversity of circumstances surrounding and challenges to end-of-life care rather than collectivizing the experience into something which can be addressed by one system of knowledge (Smith 2002). I will then analyze current legislation and future directions for end-of-life care in Hawai‘i through conversations I shared with various stakeholders.

The one system of knowledge which dominates the practice of care, biomedicine, benefits from asymmetry in structural power which privileges the ‘scientific’ voice over that of the layman. Changing the way in which care is practiced in Hawai‘i begins with altering the way in which caregivers and medical professionals alike conceptualize the act of care and the spaces in which care is practiced. This kind of change begins in the kind of small-scale setting created

by the caregiver classes, but requires participants to abandon the strict classroom setup and adopt an open forum for sharing knowledge which incorporates the expertise of tradition, lived experience, and biomedicine. Pacific scholar Linda Tuhiwai Smith concludes her book *Decolonizing Methodologies: Research and Indigenous Peoples* with the statement that "decolonization must offer a language of possibility, a way out of colonialism" (2012:324). A similar approach to breaking down the structures of biomedicine which dominate how care is practiced must provide a language through which biomedical professionals and family caregivers can find mutual understanding and respect.

Alma's Story

During one of my meetings with Alma, she proudly showed me a book her cousins had compiled which contains a detailed history of the Japanese side of her family, including photographs and original immigration documents listing details such as birthplace and occupation in Japan prior to arriving in Hawai'i. Each member of the extended family received several pages where all of the details of their life was recorded for posterity. The pride with which Alma shared the book with me was clear, and it occupies a prominent position on the bookshelf in her modest office. Not only could Alma share with me the details of her family history from memory, but despite having no siblings or remaining nuclear family I noticed her knowledge of living extended family was remarkably up-to-date.

Alma was more hesitant to discuss her own life story, and quickly began describing the individuals who she had taken care of throughout her life. As an only child born late in her mother's life, she felt that is was "a no-brainer to take care of them whenever [she] could," and quickly got her first glimpse into the life of a caregiver. Alma's parents both passed away in

2002, nine months apart, and two weeks later she found herself dropping off and picking up her biological aunt at the airport from a short trip to Las Vegas. Upon retrieving her aunt from the airport, Alma noticed her aunt had a slight cold and was not quite acting like her typical self. The first warning signals came in the form of basic questions about the trip. Alma had asked about the trip and about the well-being of various people the aunt had met with during the trip, to which her aunt responded "oh, I didn't go with her." Panic spread as Alma reminded her aunt that she knew so-and-so had been on the trip, as she had been the one to drop both of them off at the airport. Small incidences of forgetfulness similar to this are often the first sign of a larger problem, and Alma was careful to pay attention for any more strange occurrences. Unfortunately, she did not have to wait long. While Alma's aunt was quite skilled at covering up the extent to which memory problems were affecting her life, she recalled with terror one incident when she would only see the bottom half of people. Upon realizing that her aunt had experienced something truly terrifying, Alma made the decision to begin attending all of her aunt's doctor appointments and seeking more specialized medical opinions. Not long after, Alma's aunt was diagnosed with vascular dementia and Alma proceeded to be her primary caregiver for the next thirteen years until her aunt's death.

The act of providing care for another person requires a certain attention to detail that most people are unaccustomed to, a level of concern and attentiveness akin to that of a new parent. Though care recipients are often elderly individuals, Alma, like many caregivers, frequently liken her care recipients to young children or moody teenagers in both their behavior and level of cooperation. For Alma, as with the caregivers of many dementia patients, everyday life involved a certain amount of manipulation and trickery. Alma explained that for dementia patients, you have to "surrender" to their reality. In their reality, everything is normal and it is

easy to become frustrated when the caregiver gets angry or requests things which seem unreasonable. In the case of Alma's aunt, one such "unreasonable" request was the consumption of a daily bouquet of medications. Alma described how every day she would leave a harmless glass of water near the phone, and make sure all of the correct prescription medications for that day were in another cup having long abandoned the more complicated weekly medication organizers. At the required time, Alma would call her aunt under the guise of checking-in about how her day was going. During the call, Alma calmly asked her aunt for a quick favor. "Could you check and see if there's still a cup of water on the counter near the phone?" Slowly and carefully, Alma would guide her aunt through the steps of taking her medications each and every day despite significant backlash regarding "why" and "how come."

As a non-nuclear family caregiver, Alma struggled to secure funds from her aunt's personal accounts to supplement her own income in order to pay for the cost of care. Alma's aunt had no remaining nuclear family to sign the paperwork, and as her niece the banks were reluctant to allow Alma to complete the signatures. At the time, Alma's aunt still had decision-making capacity and quickly brought in financial advisors to secure new trusts and a durable power of attorney; however, Alma complained that prior to 2014 each bank had different regulations regarding durable power of attorney "so you could go to one bank like Bank of Hawaii or go to First Hawaiian Bank where she had another account, and you'd get two different ways and it depended on the bank." For many caregivers, it quickly becomes obvious that the average citizen is not educated about how to navigate the end-of-life care system or how to find services and guidance. Alma explained that at first, her biggest struggle was trying to decipher which resources were applicable to her aunt based on income and previous employment. To her despair, her aunt was not applicable for many of the programs designed to help seniors, such as Meals on

Wheels which delivers premade meals directly to the home. Alma believes this exemplifies a significant gap in end-of-life care services, where there is a "whole group of middle-income people who make too much money who has real estate that don't qualify for some of these yet they are alone…they don't have kids nearby or they've outlived their siblings."

Motivated by her long-time personal experiences as a caregiver to both her parents and her aunt, Alma found a new passion in promoting the creation of resources for family caregivers in Hawai'i. In her own words, "the struggle is what made [her] understand what the caregiver is going through" and motivated her to provide caregivers with better access to information regarding end-of-life care and services so they can make informed decision regarding the fate of their loved ones. After the experience of providing care with no prior knowledge of the resources available to seniors, Alma became determined to change the accessibility of information. Furthermore, due to socioeconomic and ethnic disparities and the current stance on affordable housing in Hawai'i, Alma does not believe current legislation is doing—or going to do—anything to assist the majority of people who live in the state. As a member of the administrative staff at a Honolulu hospital, Alma saw a clear direction towards making a difference in end-of-life care and helping disseminate information regarding various services and skills—a "grassroots" family caregiver class which could begin by pulling from the pool of patients who already visit the hospital who could then recruit friends and family.

In order to create a platform for information sharing on the level necessary to create change in community culture Alma needed help from the hospital's CEO, with whom she shared a common vision. Alma described that while the CEO had not personally experienced the burden of caregiving, their close family had a caregiving experience on the outer island of Kaua'i. They agreed that on Kaua'i "the nucleus of family is far closer but on O'ahu we're like any big,

metropolitan city where everyone kinda goes off their own way, but you know [they] realized this was something we needed to take to a different level." In order to get the CEO and the rest of the hospital executives to fully buy into to project, Alma understood they needed to see and experience care. With the help of one of the hospice managers, she hosted a meeting where the CEO role-played a bed-bound care recipient who is being moved to a wheelchair by the caregiver. She asked the CEO to "pretend that you're unable to help—you've had a stroke, you're weak—your pretend [spouse] to help you change your linen and keep you clean, how are you feeling now that you're looking up at us." The physical and emotional experience was impactful, and the caregiver classes were approved to begin in June of 2016. She attributed the hospital executive and staff's willingness to pursue such an ambitious project to their history as the first hospital in the state to offer services such as hospice, organ transplantation, and dialysis. Alma spoke at length about the hospital's longstanding commitment to keeping the community healthy, and shared that the dialysis program came out of the realization that people living in Hawai‘i could not afford to move to the mainland for treatment, a situation she likened to the current state of end-of-life services.

In the future, Alma hopes that the caregiver classes become successful enough to catch the attention of the state government. Previously the state government had stepped-in to oversee the administration of a bathing program started at the hospital, and so she hopes a similar situation will arise out of the caregiver classes' success in amending the end-of-life care navigation and information dissemination problems. Alma helped design the classes to fix the problem in several ways. Namely, she hopes that by having government officials and medical professionals come into the classroom to directly interface with family caregivers, they can provide targeted guidance which the professionals do not typically provide on their own time. In

addition, a face-to-face interface between professionals and caregivers allows for the strategic and well-planned use of scare tactics. Alma insisted that it is important for the professionals to share their "real-life scary situations" in order to "scare [the caregivers] straight" and make it clear that bad things happen to people, even in Hawai'i. According to Alma, just having a doctor lecture about what to do is not impactful enough. She was excited to announce that for an upcoming class on kidney health, they had recruited a patient on dialysis treatment to speak in order to really drive the message home and "trigger passion" in the participants. Furthermore, Alma hopes that by attending the caregiver classes people will learn to understand the unspoken rules of practicing care. For example, Alma explained:

> "one thing that was an eye-opener to the families that have come to these classes is they did not realize that the moment you say 'oh I'm taking care of auntie next door…the neighbor…' or as long as I'm taking them to the doctor on a regular basis that's saying that you are a caregiver and that's an issue when you fail to provide your services out of the goodness of your heart...it's not kosher!"

However, her main concern moving forwards it that information is clearly not reaching people early enough in life and the younger generations are not visible or present in end-of-life care conversations. Alma expressed her fear about the "seniors who try to come to these classes for themselves." I shared her concern, having seen the elderly individuals show up to the class late at night with wheelchairs, walkers, and oxygen tanks. On one occasion, an elderly man was so exhausted moving from his car to the classroom that throughout the entire class you could hear the sound of his lungs struggling to draw breath. Sometimes, she described, "you hear the panic in their voices." A growing focus of the classes offered at the hospital is planning for retirement ahead of time, beyond plans for leisure and extending into Advance Directives and finances. While the elderly demographic is panicking and going out of their way to seek out the caregiver classes, another demographic is largely absent: adolescents and young adults. Alma

wants "to see more faces that are not in the tsunami[11], younger people who are genuinely interested in correcting this situation," but as of yet there has been no success on behalf of the hospital in recruiting these people. While the "grassroots" approach has successfully spread the word to the older demographic and current caregivers, based on her own observations Alma is worried that the younger demographic do not recognize end-of-life care as an important social issue.

Patty's Story

Patty shared a similar pride of and knowledge about family, as evidenced by her relationship with her cousin Carol, another caregiver class attendee. Though she and her cousin serendipitously attended the same caregiver classes without prior discussion, Patty knew of her relationship to Carol and alerted me as to when Carol's mother passed away. These relationships further highlight the importance of family—both nuclear and extended—in contemporary Hawaiian culture. Patty was quickly able to recount how her family had arrived in Hawai'i. She described how her mother was of Chinese descent, but was born and raised on the island of O'ahu. Her father was born in Macau, and arrived in Hawai'i in 1940 to flee rising political tensions when he was only seven years old. As Patty's grandmother had remained in Macau, her father was raised by a single parent and the family quickly fell into poverty compared to the privileged lifestyle they had experienced in pre-revolution China.

Patty was extremely forthcoming about her own upbringing and young adulthood in Hawai'i. After their marriage, Patty's parents proceeded to have five children—four boys and one girl. Growing-up with four male siblings heavily influenced Patty, and as the only female

[11] The "tsunami" or "silver tsunami" is a popular metaphor for aging populations.

child she felt a strong obligation to return to Hawai‘i in order to take care of her aging parents. While growing up, Patty went to public school on O‘ahu and later attended the University of Hawai‘i at Mānoa, despite many of her childhood friends leaving the island to attend colleges on the mainland United States. Overcome by the desire to travel like so many young people in Hawai‘i, Patty traveled to Europe and eventually met her first (and later second) husband during a trip to Germany. Hawai‘i was a difficult place to live at the time due to an economic boom which drove foreign nationals to purchase real-estate and drive out local business in many lower-income neighborhoods, and Patty ended up happily staying in Germany for eighteen years. During her first ten years in Germany, she helped provide limited care to her first husband’s grandmother who had difficulty with her range of motion, including standing up and sitting down. However, when her own parents became overwhelmed with the burden of caring for themselves and a mentally ill child at home, Patty and her husband chose to return to Hawai‘i from Germany. Now, they live in a private unit within her parent’s home to provide basic care.

While Alma had taken care of her aunt for thirteen years and witnessed the worst effects of dementia, Patty is in the beginning of her journey as a family caregiver; therefore, though the burden is not less, the measures are certainly less extreme. Upon moving back to Honolulu in order to take care of her aging parents and brother, Patty immediately found the workload overwhelming. Despite working a full-time job with odd hours, Patty spends the majority of her free time at home taking care of and checking-in on her parents. Every night after dinner, she heads to her parent’s section of the home to prepare their medications, review care notes, and manages all of their appointments and medications to ensure nothing is missing or being overbilled. More and more frequently, there are small incidences where her parents demonstrate that they require someone nearby to provide hands-on care. Patty described one night where she

had just returned home from work and sat down for dinner when her father ran into the kitchen and asked Patty to check on her mother as soon as possible. When she entered their living room, Patty noticed the windows were open despite a cold storm rolling through the valley. She found her mother sitting in a chair, wearing only a thin tank top and shorts and suffering from severe chills. Patty had to transfer her mother to her bed and change her clothes, maneuvers which require significant strength and effort.

The burden of providing care while having a full-time occupation is the reality for most family caregivers living in Hawai‘i. Patty described to me how many of the nursing homes she has visited in the Honolulu area, such as Kāhala Nui and 15 Craigside, are extravagant to the point of being an “old folks home Ritz” or a “posh hotel.” Even for the relatively affordable care homes she argued that “you have to basically mortgage your home.” Clearly, many of the professional care services are designed for a wealthy demographic making them inaccessible to the vast majority of people who are part of the middle or lower socioeconomic classes. While Patty’s parents are content to remain at home, like many caregivers who attended the caregiver classes she worries that she does not possess the medical skills to provide the proper level of care and is unprepared to begin these difficult discussions with her parents. However, she did admit that her parents’ savings are not enough to pay for their own care. Despite “work[ing] hard all his life,” the 1980’s economic boom pushed Japanese investors to purchase property in the Mo‘ili‘ili neighborhood “and that’s why the price multiplied…and that’s when [Patty] was in high school and early college so [her] generation was not able to buy in.” Therefore, Patty claims the cost of living is the largest burden on her ability to provide quality care for her aging parents because she can barely “do the basic stuff now with working full-time and trying to survive here in Hawai‘i.”

For Patty, the obstacles are frequent and most often medical-related. The difficulty of communicating with various doctors and medical professionals was a constant stressor which frequently bubbled up to the surface of her psyche. Her parents visit doctors at nearly every hospital in the Honolulu area, since many specialists work only within one medical network. In order to see a neurologist you must visit Hospital A, while the bone and joint doctor is located at Hospital B. To her great chagrin, the individual doctor's offices and medical networks often fail to communicate with each other. Files and record must be manually transferred by the patient, and Patty is responsible for taking notes and relaying one doctor's words to the next. In one emotional conversation, she explained: "I take them to the doctor and I'm like well this doctor said this and oh what did he say…you're talking to a layman here…I can tell you this is what he said but what it means really? And the bigger picture and all that…do I look like I get $500,000 per year? Did I go to med school?"

Outside the hospital, the communication lapses do not give Patty a break. At the time of our interview, Patty's father required nightly therapy from a Continuous Positive Airway Pressure (CPAP) machine. While the respiratory doctor writes the prescription, a third party company is responsible for providing the machine and refill parts every three months. Patty explained the "big pain" of working with the company to ensure the correct orders are delivered. Before she took over managing the CPAP orders, her father would frequently complain that the orders were wrong or delivered at the wrong times. He shared all of the documents and order slips with Patty, but none of the pages made sense to her. After doing some research and realizing that her father was often sent incorrect supplies or billed multiple times for orders he never received, she decided to call the company and set the record straight. Over the past year, she has contacted them countless times only to find each problem more serious than the last. At

one point, she recalled that her father had two separate counts which were delivering supplies every month, rather than every three months. With extreme frustration she recalled all the hours she has spent on the phone on hold, and explained that she created a spreadsheet "that says okay we received three of five because otherwise who the hell keeps track of this shit? I don't have time to concentrate on them, I'm concentrating on this!"

Patty stumbled upon a full-page ad for the classes while reading through the free Midweek Newspaper. Upon seeing the agreeable dates and times, she decided to stop by as a precautionary measure for her aging parents to see if she could learn anything useful. According to Patty, the topics "seemed to relate to what I may need to know later on, or at least that frame of mind to be aware of, what to look for, [and] how to be prepared." She explained that while she did not really learn anything new, she thought it was "good to get a different perspective on what somebody else mentions or their ideas on what to look out for specifically." Rather than gaining new knowledge about caregiving through the planned content of the class, Patty gained meaningful insight into caregiving through her ability to interact with the other participants. She enjoyed "hearing what they're going through" and learning through shared experiences, confirming my earlier hypothesis that the caregiver classes as a forum for interaction between caregivers was one of the most impactful components. The benefit, then, of the professional lectures was a point of comparison for the skills Patty had already learned through helping care for her first husband's grandmother and her parents.

From Nostalgia to Autonomy

Alma frequently expressed concerns over the disappearance of the "plantation-style" communities in Hawai'i, "where people who lived in smaller communities close to each other…

[and] neighbors knew their neighbors and we had multigenerational families more intact than it is now." In this structure, the concept of ʻohana, which professionals like Mike are so skeptical of, ensures that elderly individuals are taken care of by the close-knit community. The problem in contemporary society, according to Alma, is that the younger generations "are not in touch with the health of their kūpuna" and are more concerned with "go[ing] off their own way," creating a lack of trust in the ability of a community to provide care. Many of the caregivers were quick to connect this ideology to their Asian lineage and culture, which places a strong historical emphasis on filial piety, or the traditional Confucian concept of respect for one's parents, elders, and ancestors.

Neither Alma nor Patty believe that the Kūpuna Caregivers Act 102 or other current legislation will change the state of end-of-life care in Hawaiʻi. Though she is part of the bill's target demographic of working caregivers, Patty had little prior knowledge about the Kūpuna Caregivers Act 102 and was largely uninterested in pursuing more information. While she was initially surprised the legislation had passed through the state government, Patty had little faith in the bill lasting more than a few years and compared it to failed public transportation projects both in Honolulu and between the different islands. Instead, she suggested that "one of the ideas that would have been better maybe instead of giving it to each individual a penny at a time is use that money…for programs to form some sort of basis where people can go to for help or information." She complained that more than a lack of money, she suffered from a lack of time to "decipher all of this what they allow or what they offer." Instead, she would prefer the state government to regulate information and create a website or central office—a single point of entry—using the money allotted to the legislation.

The importance of family and the expectations regarding care for elders within a family and community represent one theme that was repeated through my conversations with family caregivers. For both Alma and Patty, as with so many of the caregivers I met over the course of my fieldwork, assuming the responsibility of caring for their ailing parents and family members seemed to come naturally. Alma repeatedly described the decision as a "no-brainer." Professional care facilities and services were never brought into the formal decision-making process between caregiver and care recipient, through economic barriers were often taken into consideration in the caregivers' inner-monologue. In the following section, I will theorize how this unfaltering dedication and responsibility to family represents a method of claiming autonomy over end-of-life care in Hawai'i.

Returning to the idea of autonomy as the right to make one's own decisions regarding critical aspects of life, it becomes clear that family caregivers in Hawai'i lack autonomy over the practice of end-of-life care in the home. A disconnect exists between biomedicine, legislation, and the 'society' of family caregivers. Biomedicine gains the ability to divest caregivers of autonomy through capitalist processes. As caregivers and care recipients find initial hope in the biomedicine and give into its 'embrace,' they become part of a capitalist cycle which encourages them to commit to more and more biomedical interventions and technologies (DelVecchio Good 2007). As evidenced throughout ethnographic accounts with family caregivers, the economic realities and social pressures of living in Hawai'i eventually cause biomedicine to loosen its hold over how care is practiced in the home.

The longing Alma feels for the "plantation-style communities" of colonial-period Hawai'i can be understood through the lens of biomedical nostalgia. The term nostalgia "implies a specific positioning towards the past seen as irreversible, an awareness of something which has

disappeared or is disappearing" (Angé and Berliner 2014:11). Furthermore, nostalgia is "a force that does something," or forces a particular response (Dames 2010:272). For family caregivers, like Alma, biomedical nostalgia is twofold. First, it is about a desire for a time before biomedicine and is necessitated by a need to get away from the control of biomedicine over end-of-life care. Second, it is about the disappearance of social connectivity—which compels a particular practice of care—and giving voice to contemporary social and political desires.

In the case of end-of-life care in Hawai'i, autonomy is about biomedicalization. Alice Street demonstrates a comparable situation in her book *Biomedicine in an Unstable Place: Infrastructure and Personhood in a Papua New Guinean Hospital* (2014). In the wake of colonial governance, provincial hospitals in Papua New Guinea struggled to improve infrastructure and implement biomedicine in order to provide security in a postcolonial state. Here, biomedicine is not a colonial object as postcolonial Papua New Guineans build upon existing hospital infrastructure in the process of building a new nation-state. Similarly, in order to achieve autonomy over care past all of the legislation and power structures in Hawai'i, family caregivers—and more specifically, families—must be the ones who have control over the practice of care and the incorporation of biomedical technologies and interventions. Medical professionals, family caregivers, and care recipients must work together to develop an biomedicalized approach to care which encompasses the community-driven social connections called for by the caregivers with whom I shared conversations. By building upon and fostering the existing infrastructure of caregiver classes, caregiver support groups, and activist organizations I believe medical professionals and family caregivers have already taken the first steps in reclaiming autonomy over care in Hawai'i.

CHAPTER FIVE
CONCLUSION: THE FUTURE OF CARE

Introduction

In concluding this ethnography, I discuss both the uncertain future of end-of-life care in Hawai‘i and the equally precarious future of the family caregiver classes. End-of-life care in Hawai‘i represents a complicated intersection between standards for biomedical care and the realities of how end-of-life care is practiced within the home based on a variety of social and economic limitations. Family caregivers are often forced to choose between what is deemed correct by the biomedical community of doctors and practitioners and what is feasible for their daily lives. In this way, family caregivers are necessarily noncompliant with the biomedicine practice of end-of-life care. The family caregiver classes documented throughout this ethnography attempt to bridge this gap and make the biomedical practice of end-of-life care accessible to caregivers with varying and uncertain degrees of success.

Throughout this thesis, I have demonstrated how the theoretical themes of biomedicine as social control, citizenship and autonomy, and the body as the locus of meaning are omnipresent in the lives of family caregivers in Hawai‘i. As biomedicine exerts more and more control over the body and the practice of care, caregivers are forced to turn to biomedical nostalgia in a search for autonomy over end-of-life care. Medical professionals uphold structures of biomedical power in their work and in the way they teach caregiver classes; however, family caregivers subvert this structure of power through the ways in which they provide care in the home. Through this practice, caregivers transform the biomedical knowledge of professionals into knowledge which can be mobilized for a more social concept of care.

As I conclude this research, I hope to benefit those individuals who have dedicated their time to improving end-of-life care in Hawai‘i. The major contribution which I hope readers can

take away from this thesis is the importance of allowing caregivers, medical professionals, and care recipients time to collectively process and understand the plethora of information generated through the practice and study of end-of-life caregiving. These groups need time in which to interact face-to-face and talk through questions and concerns. In an effort to meet this goal, I will provide some professional recommendations for policy and future research which resulted from my field research and interactions with medical professionals, activists, and family caregivers. I also find it necessary to note that in no way does this thesis research provide a comprehensive look at the entirety of end-of-life care in Hawai‘i. Namely, the native Hawaiian population was entirely absent from this research, though they experience even more dispossession and suffering in the face of settler colonialism and a loss of autonomy over end-of-life care. Therefore, I urge my fellow social scientists to take seriously the well-being of aging communities in the face of the biomedical hegemony, particularly in those communities who are already marginalized.

The Future of End-of-Life Care

Honolulu, like most major cities in the United States, is constantly undergoing processes of gentrification, development, and policy change at both the federal and state levels. Unique to Honolulu are the additional—yet intermingled—forces of tourism and settler colonialism which consume entire neighborhoods in order to build the new restaurants, high-rise apartments, and luxury grocery stores which fuel these enterprises. As new arrivals to Hawai‘i flood the service industry, including end-of-life care facilities, families who have lived in Hawai‘i for generations are forced to seek other creative options. Recall Patty’s description of the transformation of the Mo‘ili‘ili neighborhood of Honolulu, located near the University of Hawai‘i at Mānoa campus, which experienced a transformation in the 1980s as an economic boom allowed Japanese

investors to purchase property without regulation from politicians. Local families, such as Patty's, are forced to move further from central Honolulu and the services available in urban centers. Tim explained how the process of settler colonialism results in care homes and other end-of-life services becoming overburdened, leaving little to no room for the average family from Hawai‘i, particularly those from the outer islands. Furthermore, what facilities are left available are often at rates too expensive for predominantly middle class 'locals.'

Though interviews with Alma, Patty and other professionals and activists involved in the end-of-life care network in Hawai‘i, I became privy to underlying dissatisfaction with the existing legislation and support networks for end-of-life family caregivers. In one early interview with long-time members of local end-of-life care organizations and activism groups, I learned that a major concern is the lack of time caregivers have to seek out the resources provided through the efforts of such groups. These professionals noted that the average caregiver in Hawai‘i does not have the time for conversations, information sessions, or training. Furthermore, the vast majority of family caregivers never even seek out these resources due to time constraints, let alone attend something as time consuming as the family caregiver classes which form the backbone of this ethnography. For example, Patty shared with me that had she not lived in the general location in which the caregiver classes are hosted, she would never have attended the few sessions in which she participated. Between working multiple jobs—with demanding, competitive hours—and providing care to her elderly parents, she has little time left over for seemingly superfluous activities such as attending a caregiver class.

During a conversation with Patty, we discussed what the Hawai‘i state government is doing to alleviate these problems. While largely unaware of the recent legislation—Kūpuna

Caregivers Act 102—directed towards alleviating the economic burden on family caregivers through a government provided stipend, Patty was uninterested in learning more. She stated:

> I don't know much about the bill that was passed or where it stands. I think it's good that Hawai'i has more of a history of being a little more people-oriented. This is a big generalization, but we try to look out for each other…so to see it pass in any kind of political way is surprising. It's a very democratic senate so in that sense it had an easier chance of passing, but for it even to be brought up since all we do is fight about finance and like the super ferry that went away…that went down the tubes…anyway a lot of it is surprising that it passed. One of the ideas that would have been better maybe instead of giving it to each individual a penny at a time is use that money for programs to form some sort of basis where people can go to for help or information…these pennies that should have gone to some sort of city or state entity could be a basis to get started on getting the information out to everyone, or something that can get information to people that need it. If there are so many caretakers on this island—or the United States for that matter—why has no one said 'go to this website and check out this or this organization.' I don't have time to decipher all of this what they allow or what they offer. Can't we make this part of the government where it's regulated? Or not even regulated, but it comes from them from a standard office and this is how it's done? But no. You don't know if these people are legit. I mean the stuff I have to do to just take care of my parents is ridiculous. I'm not even talking about dealing with organizations, but I mean dealing with Medicare, dealing with their medications, dealing with their doctors….there's no one single place.

While professionals are conscientious of the time limitations family caregivers face in seeking out information, they still maintain the expectation that the caregivers will come to them. Patty, however, voices the popular opinion that the government and professionals should be more proactive and bring the information to the caregivers either in the form of a central government-sponsored information hub or better distribution directly from medical professionals. With this insight in mind, the family caregiver classes are uniquely positioned as a place of change and potential reformation of end-of-life care in Hawai'i.

Caregiver Classes and Beyond

Over the course of the past year, the family caregiver classes have continued to see an increase in participation. Each class session returning participants are joined by more and more

new participants who learn about the courses through advertisements or word-of-mouth. As a result, the classes have quickly outgrown their original location in a small classroom space located within one of the office buildings on the hospital campus. While nearly sixty participants may inquire about a class session, many are limited to only ten participants. To meet the needs of the growing elderly population of Hawai‘i, the hospital in question plans to build a hospital campus dedicated to facilities, doctors, and medical services specifically for this demographic. While the caregiver class organizers planned to relocate the classes to the new multi-purpose facility located on this campus, construction delays have forced the classes to remain in their current location.

The caregiver classes have undergone little change to content and instructors over the past year, as well. Many of the professional instructors are the same individuals who have been volunteering to teach class sessions for the past several years, resulting in repeated topics and content. While the dedication of these outstanding individuals should not go unnoticed, caregivers are unlikely to continue attending the classes in the long-term if they are not receiving new, meaningful information. In addition to these central, thematic class sessions, I would recommend the introduction of reoccurring general information sessions for family caregivers to alleviate the need for a central location for information about end-of-life care. Furthermore, the class sessions could be intermixed with workshops, in which family caregivers can practice hands-on skills such as cooking healthy meals or completing necessary documents.

I do not mean to imply that the caregiver classes should cease to exist; in fact, I believe that the caregiver classes offered through the hospital offer a crucial element which is lacking throughout the remainder of end-of-life care services. Through the classes, medical professionals and family caregivers are allowed crucial face-to-face interaction outside of a clinical setting

which creates a unique dialog with the capability to improving end-of-life care. The most important interactions I observed during my observation of the classes was the candid interaction between these two groups, which allows for learning on both sides. Family caregivers are able to learn about the clinical aspects of caregiving, while medical professionals are exposed to the challenges and lived experiences of family caregivers.

Conclusion

End-of-life care in Hawai‘i is multifaceted and in constant flux. The idealized, professionally-mediated care practiced in nursing facilities and care homes is often a far cry from the resourceful style of care practiced by family caregivers. Throughout this ethnography, I described how the tension between biomedicine’s inherent control over bodies and family caregiver agency results in noncompliance in the way in which care is practiced within the privacy of the home. While medical professionals uphold the biomedical power structure, family caregivers subvert this power structure and reinforce social connections and familial power structures. Through these actions, caregivers transform the biomedical knowledge of professionals into knowledge which can be mobilized for a more social or relational concept of care. In searching for autonomy over this practice of socially-based care, caregivers invent a biomedical nostalgia for a more connected community which serves as a powerful mechanism for relocating power over care into the home.

Health services and end-of-life care will never be perfect; however, Hawai‘i is actively making space for these conflicts to play out and being receptive to innovative change. Family caregivers, medical professionals, and activists are finding time to meet and discuss areas for improvement and voicing dissatisfactions with the current system which will make way for even

more effective change in the future. Rather than focusing on how care is being practiced and policing the 'appropriate' practice of care, I encourage these dedicated individuals to focus on the systemic and policy-driven causes for why individuals are forced to overcome economic, temporal, and personal hurdles in the search for adequate care.

BIBLIOGRAPHY

Abu-Lughod, Lila
1990 Can There be a Feminist Ethnography? Women and Performance 5(1):7-27.

Agamben, Giorgio
1998 Homo Sacer: Sovereign Power and Bare Life. Stanford University Press.
2005 State of Exception. Kevin Attell, trans. The University of Chicago Press.

American Association of Retired Persons
2011 Prepared to Care? Hawaii AARP Members' Opinions on Caregiving and Long-Term Care. Research Report. Washington, D.C.: AARP Research and Strategic Analysis.

American Association of Retired Persons
2015 Caregiving in the U.S.. Research Report. Washington, D.C.: AARP Public Policy Institute.

Angé, Olivia and David Berliner, ed.
2014 Anthropology and Nostalgia. Berghahn Books, Incorporated.

Becker, Gay
2002 Dying Away From Home: Quandaries of Migration for Elders in Two Ethnic Groups. Journal of Gerontology 57(2):79-95.

Berlant, Lauren
2007 Slow Death: Sovereignty, Obesity, Lateral Agency. Critical Enquiry 33(4):754-780.

Bissell, William Cunningham
2005 Engaging Colonial Nostalgia. Cultural Anthropology 20(2):215-248.

Bourdieu, Pierre
1992 The Logic of Practice. Stanford University Press.

Briggs, Charles L., with Clara Mantini-Briggs
2004 Stories in the Time of Cholera: Racial Profiling during a Medical Nightmare. University of California Press.

Buch, Elana D.
2015 Anthropology of Aging and Care. Annual Review of Anthropology 44:277-293.

Clarke, Adele E.
2010 From the Rise of Medicine to Biomedicalization: U.S. Healthscapes and Iconography, circa 1980 to Present. *In* Biomedicalization: Technoscience, Health, and Illness in the U.S.. Adele E. Clarke, Laura Mamo, Jennifer Ruth Fosket, Jennifer R. Fishman, and Janet K. Shim, eds. Pp. 104-146. Duke University Press.

Clarke, Adele E., with Janet K. Shim, Laura Mamo, Jennifer Ruth Fosket, and Jennifer R. Fishman
2003 Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine. American Sociological Review 68:161-94.

Clifford, James
2013 Returns: Becoming Indigenous in the Twenty-First Century. Cambridge: Harvard University Press.

Collins, Randal
1994 Four Sociological Traditions: Selected Readings. Oxford: Oxford University Press.

Conklin, Beth A. and Lynn M. Morgan
1996 Babies, Bodies, and the Production of Personhood in North America and a Native Amazonian Society. Ethos 24(4):657-694.

Cox, Aimee Meredith
2018 Afterword: Why Anthropology? Hot Spots, *Cultural Anthropology* website. https://culanth.org/fieldsights/1539-afterword-why-anthropology

Csordas, Thomas J.
1990 Embodiment as a Paradigm for Anthropology. Ethos 18(1):5-47.

Dames, Nicholas
2010 Nostalgia and Its Disciplines. Memory Studies 3(3):269-275.

DelVecchio Good, Mary-Jo
2007 The Medical Imaginary and the Biotechnical Embrace: Subjective Experiences of Clinical Scientists and Patients. In Subjectivity: Ethnographic Investigations. Joao Guilherme Biehl, Byron Good, and Arthur Kleinman, eds. Pp. 362-380. Berkeley: University of California Press.

Desjarlais, Robert and C. Jason Throop
2011 Phenomenological Approaches in Anthropology. Annual Review of Anthropology 40:87-102.

Diedrich, Lisa
2011 Speeding Up Slow Deaths: Medical Sovereignty Circa 2005. MediaTropes eJournal 3(1):1-22.

Farmer, Paul
1992 AIDS and Accusation: Haiti and the Geography of Blame. University of California Press.

Field, David
1996 Awareness and Modern Dying. Mortality 1(3):255-265.

Foucault, Michel
1975 The Birth of the Clinic: An Archaeology of Medical Perception. New York: Pantheon Books.
1978 The History of Sexuality. New York: Pantheon Books.
1980 Power/Knowledge: Selected Interviews and Other Writings. New York: Pantheon Books.
1988 Technologies of the Self: A Seminar with Michel Foucault. L. H. Martin, H. Gutman, and P. H. Hutton, eds. Amherst, MA: University of Massachusetts Press.
1991 Governmentality. *In* The Foucault Effect. G. Burchell, C. Gordon, and P. Miller, eds. Pp. 87-194. Brighton, England: Harvester Wheatsheaf.

Gjødsbøl, Iben M., with Lene Koch, and Mette N. Svendsen
2017 Resisting Decay: On Disposal, Valuation, and Care in a Dementia Nursing Home in Denmark. Social Science & Medicine 184:116-123.

Goffman, Erving
1961 Asylums: Essays on the Social Situation of Mental Patients and other Inmates. Anchor Books.
1967 Interaction Ritual: Essays on Face-to-Face Behavior. Anchor Books.

Good, Byron J.
1994 Medicine, Rationality, and Experience: An Anthropological Perspective. Cambridge: Cambridge University Press.

Griffin, Catherine Mcleod
2012 It's a Birth, Not a Procedure: An Ethnographic Study of Intrauterine Fetal Death in a Labor and Delivery Unit of an American Hospital Setting. Ph.D. dissertation, Wayne State University.

Gupta, Akhil
2012 Red Tape: Bureaucracy, Structural Violence, and Poverty in India. Duke University Press.

Haraway, Donna Jeanne
1991 Simians, Cyborgs, and Women: The Re-Invention of Nature. London: Free Association.

Harrison, Faye V.
2010 Anthropology as an Agent of Transformation: Introductory Comments and Queries. In *Decolonizing Anthropology: Moving Forward toward an Anthropology for Liberation*, F.V. Harrison, ed., pp.1-15. Third Edition. Arlington: American Anthropological Association.

Heidegger, Martin
2010 Being and Time. Joan Stambaugh, trans. Dennis J. Schmidt, revs. Albany, New York: SUNY Press.

Hertz, Robert
1960 Death and the Right Hand. Glencoe: Free Press.

Husserl, Edmund
1970[1936/54] The Crisis of European Sciences and Transcendental Philosophy. D. Carr, trans. Evanston: Northwestern University Press.

Joyce, Kelly A.
2008 Magnetic Appeal: MRI and the Myth of Transparency. Cornell University Press.

Kauanui, J. Kehaulani
2018 Paradoxes of Hawaiian Sovereignty: Land, Sex, and the Colonial Politics of State Nationalism. Durham: Duke University Press.

Latour, Bruno and Steve Woolgar
1979 Laboratory Life: The Construction of Scientific Facts. Beverly Hills: Sage Publications.

Legal Information Institute
2015 § 71.25 Approval and designation of Primary and Secondary Family Caregivers. Electronic Document, https://www.law.cornell.edu/cfr/text/38/71.25

Lock, Margaret
1993 Cultivating the Body: Anthropology and Epistemologies of Bodily Practice and Knowledge. Annual Review of Anthropology 22:133-155.

Martin, Emily
1987 The Woman in the Body: A Cultural Analysis of Reproduction. Boston: Beacon Press.

Marx, Karl and Frederick Engels
2001 The German Ideology, Part One, with Selections from Parts Two and Three, Together with Marx's "Introduction to a Critique of Political Economy." C.J. Arthur, trans. New York: International Publishers.

Mauss, Marcel
1968 Sociologie et Anthropologie. Paris: Presses Universitaires de France.

McMullin, Juliet Marie
2010 The Healthy Ancestor: Embodied Inequality and the Revitalization of Native Hawaiian Health. Walnut Creek, California: Left Coast Press.

Merleau-Ponty, Maurice
1964[1958] Phenomenology and the Sciences of Man. John Wild, trans. *In* The Primacy of Perception. James Edie, ed. Evanston: Northwestern University Press.
1973[1949] Consciousness and the Acquisition of Language. Hugh J. Silverman, trans. Evanston: Northwestern University Press.
2012[1945] Phenomenology of Perception. Donald A. Landes, trans. New York: Routledge.

Petryna, Adriana
2013 Life Exposed: Biological Citizens after Chernobyl. Princeton University Press.

Raheja, Michelle H.
2013 Reservation Reelism: Redfacing, Visual Sovereignty, and Representations of Native Americans in Film. Lincoln: University of Nebraska Press.

Scheper-Hughes Nancy and Margaret M. Lock
1987 The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology. Medical Anthropology Quarterly 1(1):6-41.

Simpson, Audra
2014 Mohawk Interruptus: Political Life Across the Borders of Settler States. Duke University Press.

Smith, Linda T.
2012 Decolonizing Methodologies: Research and Indigenous Peoples. Second edition. London: Zed Books.

Street, Alice
2014 Biomedicine in an Unstable Place: Infrastructure and Personhood in a Papua New Guinean Hospital. Durham: Duke University Press.

Towey, Maureen
2017 Easing the Burden on Caregivers. New York Times, December 15.

van der Geest, Sjaak, with Susan Reynolds Whyte, and Anita Hardon
1996 The Anthropology of Pharmaceuticals: A Biographical Approach. Annual Review of Anthropology 25:153-178.

Warrior, Robert Allen
1994 Tribal Secrets: Recovering American Indian Intellectual Traditions. Minnesota: University of Minnesota Press.

West, Paige
2016 Dispossession and the Environment: Rhetoric and Inequality in Papua New Guinea. New York: Columbia University Press.